

University of Denver

Digital Commons @ DU

Electronic Theses and Dissertations

Graduate Studies

1-1-2013

The Last Citizen: A Response to Rawls's Challenge on Impairment—a Third Principle of Justice, and Extra-Rational Contribution

Michael Neil
University of Denver

Follow this and additional works at: <https://digitalcommons.du.edu/etd>

Recommended Citation

Neil, Michael, "The Last Citizen: A Response to Rawls's Challenge on Impairment—a Third Principle of Justice, and Extra-Rational Contribution" (2013). *Electronic Theses and Dissertations*. 472.
<https://digitalcommons.du.edu/etd/472>

This Dissertation is brought to you for free and open access by the Graduate Studies at Digital Commons @ DU. It has been accepted for inclusion in Electronic Theses and Dissertations by an authorized administrator of Digital Commons @ DU. For more information, please contact jennifer.cox@du.edu, dig-commons@du.edu.

The Last Citizen
A Response to Rawls's Challenge on Impairment:
A Third Principle of Justice, and Extra-Rational Contribution

A Dissertation

Presented to

the Faculty of the Josef Korbel School of International Studies

University of Denver

In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

By

Michael Russell Neil

March 2013

Advisor: Alan Gilbert

Author: Michael Russell Neil

Title: The Last Citizen: A Response to Rawls's Challenge on Impairment:
A Third Principle of Justice, and Extra-Rational Contribution

Advisor: Alan Gilbert

Degree Date: March 2013

Abstract

John Rawls, in *Political Liberalism*, acknowledges that *justice as fairness*, as it stands, “may fail” to deliver justice to people with severe cognitive impairment. He continues, “How deep a fault this is must wait until the case itself can be examined.”¹ The intent of this work, then, is to revisit Rawls's justice as fairness in light of intervening decades of disability consciousness and the emergence of competing theoretical constructs pertinent to the lives of people with impairment, specifically to people with an inability to reason or to reason fully, and determine whether new perspectives can expand its scope into a more comprehensive model.

A fully democratic theory of justice cannot exclude the “hard cases,” so in addition to Rawls's two principles of justice, the author will argue that a third principle of justice must be included to assure true democratic outcomes. The new principle will state: *All structures arising from the first two principles must be open to all human beings—fully inclusive—without exception.* The author expects that this third principle will be embraced by the reasonable and rational designers because it is in their self-interest to do so. The concept of self-interest—that interest, which might sway a person's choices toward personally favorable outcomes—is seen, by this author, as inclusive of favorable outcomes for all people with whom the designer self-identifies. Arenas of self-

¹ John Rawls, *Political Liberalism: With a New Introduction and The “Reply to Habermas”* (New York, New York: Columbia University Press, 1993), 21.

interest expand past the boundaries of an individual's actual person and past the confines of time, to encompass others, including one's future self, whose well-being is of such importance to the designer as to define her own well-being.

Rawls means to assure a form of empathetic behavior when he constructs the veil of ignorance. In the original position, because the designer is veiled from all of his individual characteristics, Rawls forces consideration of the circumstances of every possible person the designer could be. The designer must consider those of all possible ethnicities, cultures, genders, classes, economic brackets, endowments, and other individual characteristics. Yet, the veil can never hide from the designer the fact that she can reason, and, if the designer were to make choices based on a narrow version of self-interest, the circumstances of people with cognitive impairment would remain unconsidered. Yet, people actually act within a broader definition of self-interest. The veiled designer cannot know if impairment affects his child or others with whom he identifies, nor can he know, given the nature of impairment, whether he will become impaired imminently or in the future. The unpredictable and non-discriminating nature of impairment means that its lack of consideration in the original position will expose participants, who all have impairment in a potential state, to the consequences of policy, which fails to address circumstances that might define anyone's future. Within an expanded notion of self-interest, the circumstances of people with severe cognitive and physical impairment will be represented because, among many reasons, it is personally advantageous for participants to do so.

The social relevance of people with cognitive impairment, the author will argue, highlights the need for a theoretical restructuring of concepts of contribution and value,

beyond rationality, that would lead to a reconceived notion of rights-bearing status and positions of respect. Can theory redefine personhood in a non-traditional way that can, but need not, include the ability to make moral choices, in order to extend value to previously excluded individuals, who nonetheless benefit society through extra-rational contribution? The author will explore the contributions and subsequent value to society of people with cognitive impairment (and all impairment, for that matter). Notions of value should not be confused with ideas of intrinsic human worth. Acceptance of the latter does not lead individuals seeking community, based on mutual advantage, to court the participation of a non-contributor. Only social valuing can uproot the entrenched notion of worthlessness inherent in terms like “useless eaters.”

For all people, life as a human being involves living inside a vessel, which is subject to entropy, disease, injury and imperfection. Historically, society has sequestered those who provide reminders of the frailty of the human body and mind, and in so doing has doggedly clung to a chosen, comfortable illusion. What has been lost in this collective behavior is the opportunity to lead truly authentic lives, to embrace and incorporate the complete human experience. People with impairment can lead us in claiming our full humanity and in so doing make an invaluable contribution.

Author's Note

The author realizes that the distinction between the terms *impairment* and *disability* is not always clear in other works or in society's lexicon. Following much of the scholarship in the disability community, as well as the definition of the World Health Organization, the author uses the term *impairment* to describe a physical or mental condition, while the term *disability*, on the other hand, refers to the consequences of the intersection of an impaired mind or body and a society, which is constructed without consideration for those with impairment.

The author would also like to explain the extensive use of block quotations within the work. Often, works in philosophy and related disciplines truncate quotes or paraphrase in ways that support their objectives. In researching this work, the author looked up a vast number of citations and was astonished to find that his reading of the original and complete quote had little in common with the way in which it was cited in the secondary text. By providing more complete quotes, the author hopes to give the reader the actual flavor of the original. More importantly, the author has provided quotes of substantial length when citing the words of his fellows with impairment. For so long, people with impairment have been shut up, literally and figuratively, and in acknowledgement of the important history that has only begun to be told, the author feels a strong need to let those, who are the subject of this work, tell their own stories without edit or manipulation.

Table of Contents

Abstract.....	ii
Author's Note.....	v
Table of Contents.....	vi
Prologue.....	1
Chapter One: Moral Consideration, Citizenship and People with Severe Cognitive Impairment.....	7
Chapter Two: Investigation of Theories that Consider People with Severe Cognitive Impairment.....	20
Care Theory.....	20
Peter Singer Knows I Suffer.....	59
Fear of Difference, Avoidance, and the Legacy of Isolation.....	95
Chapter Three: Reasonably Confused: Human Rights and Cognitive Impairment.....	104
Chapter Four: A Challenge to Rawls and an Introduction to the Capabilities Approach....	119
Chapter Five: A Response to Rawls' Challenge on Impairment.....	163
Epilogue.....	182
Bibliography.....	186

Prologue

Identification of the Problem

Life is like a box of chocolates. You never know what you're gonna get.--Forrest Gump

A family rushes to the hospital, full of anticipation and a little trepidation. "As long as it's healthy." Never are human beings more at the mercy of fate than just before a baby is born. Families and friends wait while the woman, who has carried, dreamed about, and talked to the developing fetus for nine months, struggles with the birth, her husband at her side. Finally, the new baby arrives. He seems robust, with a strong tendency to voice his opinion. A nurse wraps him and gives him to his mother to hold. She cannot quite meet the mother's eye. The delivering doctor talks to the new parents, offering congratulations, but with no joy in his expression. Birth photos show a gowned man, shaking hands, who might as well be delivering the news that someone has died. The mother and father find themselves in a hazy, stunned reality. The neurosurgeon arrives to sit with the family and determine whether to save the baby's life. The doctor outlines every possible negative outcome and explores each possible deficit. The parents should think about allowing the baby to die. They are to give it consideration. The doctor will return in a couple of hours. Neither mother nor father can recall exactly what the doctor said, what he called their baby's anomaly, or what they must take under

consideration, but both are clear that life will now change forever and neither is prepared to be a passive executioner. One bit of information to hold tight to—the baby’s diagnosis generally does not include cognitive impairment. He still might go to college; he still might fulfill family traditions of academic excellence.

This is the author’s birth story and though the challenges of a learning disability, leg paralysis, and less than fully functional arms make his journey somewhat more laborious, he has achieved a level of academic success and looks forward to getting up in the morning. People patronize the author, using words like “amazing” and “inspiring” when describing him, as if his accomplishments are miraculous given his impairments. Had he not possessed the intellectual tools to “overcome” his disability, would he still be considered a contributor, or would the mantle of “burden” accompany him throughout life?

A second birth story begins in about the same way as the first. This time, however, doctors immediately identify the baby as having a syndrome, the components of which include severe cognitive impairment. The new parents are also overwhelmed and sadness pervades the hospital room. When it comes time to go home, the paternal grandmother pulls the new mother aside and articulates society’s assumptions and prejudices. How can the mother think of making a life with this child? He will ruin their lives, deflect all attention away from his typical toddler sister, destroy his father’s social standing, and he will suffer. She should instead put him “away” where he will not be able to destroy their family. There is absolutely no expectation that this baby has anything to contribute. His grandfather refers to him as “poor kid.”

When a child is born with a condition known to cause severe cognitive impairment, is parental suffering simply a result of the current condition of the baby or preconceived social notions of future deficits concerning beauty, success, and acceptability? In what ways do philosophical conceptions contribute to this family's pain? How have centuries of theory conditioned society in acceptance of the notion that, without reason, individuals are less than human or fail to merit life, or are more removed from the divine than their rational neighbors?

The gods plant reason in mankind, of all good gifts the highest.²

--Sophocles

Stranger: And in the soul there are two kinds of evil.

Theaetetus: What are they?

Stranger: The one may be compared to disease in the body, the other to deformity.

Theaetetus: I do not understand.

Stranger: Perhaps you have never reflected that disease and discord are the same.

Theaetetus: To this, again, I know not what I should reply.

Stranger: Do you not conceive discord to be a dissolution of kindred elements, originating in some disagreement?

Theaetetus: Just that.

Stranger: And is deformity anything but the want of measure, which is always unsightly?

Theaetetus: Exactly.

Stranger: And do we not see that opinion is opposed to desire, pleasure to anger, reason to pain, and that all these elements are opposed to one another in the souls of bad men?

Theaetetus: Certainly.

Stranger: And yet they must all be akin?

Theaetetus: Of course.

² Sophocles, "Antigone" trans. Sir George Young in *World Drama: An Anthology, Vol. I: Ancient Greece, Rome, India, China, Japan, Medieval Europe, and England*, ed. Barrett H. Clark (New York, New York: Dover Publications, 1960), 31.

Stranger: Then we shall be right in calling vice a discord and disease of the soul?

Theaetetus: Most true.

Stranger: And when things having motion, and aiming at an appointed mark, continually miss their aim and glance aside, shall we say that this is the effect of symmetry among them, or of the want of symmetry?

Theaetetus: Clearly of the want of symmetry.

Stranger: But surely we know that no soul is voluntarily ignorant of anything?

Theaetetus: Certainly not.

Stranger: And what is ignorance but the aberration of a mind which is bent on truth, and in which the process of understanding is perverted?

Theaetetus: True.

Stranger: Then we are to regard an unintelligent soul as deformed and devoid of symmetry?

Theaetetus: Very true.³

--Plato

Contemplation is both the highest form of activity (since the intellect is the highest thing in us, and the objects that it apprehends are the highest things that can be known)...⁴

--Aristotle

To disparage the dictate of reason is equivalent to condemning the command of God.⁵

--Aquinas

³ Plato, *The Dialogues of Plato: Translated into English with Analyses and Introductions* vol. 3, ed. and trans Benjamin Jowett (London, United Kingdom: MacMillan and Company, 1892), 488-489 (228 A-B).

⁴ Aristotle, *Nicomachean Ethics*, ed. and trans. Martin Ostwald (Englewood Cliffs, New Jersey: Prentice Hall, 1962), 1177a12- 23.

⁵ Thomas Aquinas. *Thomas Aquinas: Philosophical Texts*, ed. and trans Thomas Gilby (Oxford, United Kingdom: Oxford University Press, 2003), 284.

Man is obviously made for thinking. Therein lies all his dignity and his merit...⁶

--Pascal

(God gave the World) to the use of the Industrious and Rational...⁷

--Locke

Without doubt there is a universal justice emanating from reason alone...⁸

--Rousseau

Nature gave man reason, and freedom of will based upon reason, and this in itself was a clear indication of nature's intention as regards his endowments.⁹

--Kant

In fact, it is a farce to call any being virtuous whose virtues do not result from the exercise of its own reason.¹⁰

--Wollstonecraft

⁶ Blaise Pascal, *Pensées*, ed. and trans. A.J. Krailsheimer (London, United Kingdom: Penguin Books Ltd, 1995), 207. (Section II, Part XXIV, n. 620 (Brunschvig no. 146)).

⁷ John Locke, *Two Treatises of Government*, ed. Peter Laslett (Cambridge, United Kingdom: Cambridge University Press, 1988), 291.

⁸ Jean-Jacques Rousseau, *The Social Contract and the First and Second Discourses*, ed. Susan Dunn and trans. Lester Crocker and Susan Dunn, (New Haven, Connecticut: Yale University Press, 2002), 178.

⁹ Immanuel Kant, *Political Writings*, ed. Hans Siebert Reiss and trans. Hans Siebert Reiss and H.B. Nisbet (Cambridge, United Kingdom: Cambridge University Press, 1991), 43. sefjaeger@comcast.net

¹⁰ Mary Wollstonecraft, *A Vindication of the Rights of Woman*, ed. Miriam Brody (London, United Kingdom: Penguin Books Ltd., 2004), 31.

The irrational in the human has something about it altogether repulsive and terrible, as we see in the maniac, the miser, the drunkard, or the ape.¹¹

--Santayana

¹¹ George Santayana, *The Life of Reason; Or, The Phases of Human Progress: Reason in Society* (New York, New York: Scribner and Sons, 1906), 69.

Introduction

The Democratic Society, Equal Consideration, and People with Severe Cognitive Impairment

It will be seen how in the place of the wealth and poverty of political economy, come the rich human being and rich human need. The rich human being is simultaneously the human being in need of a totality of human life-activities—the man in whom his own realization exists as an inner necessity, as need.-- Karl Marx, The Economic and Philosophical Manuscripts of 1844.

Western philosophical tradition has identified the quality of rationality as that which uniquely delineates *personhood* or *moral personhood*. A *moral person* possesses a *self*, defined as that which is conscious of its own identity, and this inherently rational ability is the essential characteristic used in conferring value and subsequent status allowing democratic participation. Because theory has largely understood participation as rational contribution, it has separated reason from, and elevated it above, what is, in reality, a compendium of physical, emotional, spiritual, and relational components in synergy within a human being. Professor Eva Feder Kittay states:

...personhood marks the moral threshold above which equal respect for the intrinsic value for an individual's life is required and the requirements of justice are operative and below which only relative interest has moral weight.¹²

¹² Eva Feder Kittay, "At the Margins of Moral Personhood," *Ethics* 116 (Oct. 2005): 101.

The philosophical tradition of dividing people into *persons* and *non-persons* based on rationality speaks to society conferring status based on the potential for understanding one's ends and the means to reach them and for choosing actions in conformity with socially determined ethical behavior. If an entity is a *person*, his existence places limitations on the actions of other *persons* insofar as their freedoms are concerned. If an individual lacks rationality, his existence places no such limitations. He is a *non-person* devoid of social responsibility because he is unable to perform *duties*—unable to discern what is moral from what is not and therefore unable to participate in a reciprocal (cooperating) relationship. Historically he has been demeaned as a “useless eater,” “idiot,” “moron,” “imbecile,” or “retard.”

The twenty-first century is witness to a contentious theoretical and real-life struggle waged by a group, inclusive of individuals with cognitive impairment who have never, in the history of the world, been embraced as fellows, as part of a human matrix seeking self-knowledge and justice through a balancing of liberty and equality. Instead they have been feared, reviled, imprisoned, tortured, and murdered because, instead of being seen as part of the human cooperative, demonstrating the potential future state of any currently rational human being, they are seen as freaks of nature, burdens on society, and generators of ontological anxiety. Because the non-impaired vaguely sense that people with impairment reflect the potential state of any human being, yet cannot bear to look into this mirror of future possibility, they disown their own potential selves by “othering” people with impairment, thus denying the corporeal fragility inherent in the human condition. If those with impairment represent that which is alien, it is easier to

condone their institutionalization, sterilization, euthanizing, and sequestration. It is easier to deprive them of liberty, authority, self-determination, and control. Society need not extend democratic principles to “sub-humans” and there is a history of denying participation to various outlier groups, whose participation in some way threatened the status quo. Thus, substantive democracy has never existed. Society has slowly and painfully moved ever closer, but until people with impairment are considered part of the human family, instead of unfortunate anomalies, society cannot be considered truly democratic.

A theory of justice that seeks to be universal must provide all members of society, including those who lack rationality, with a means toward consideration of their well-being and a procedure through which they might play a role in the design of a just society. Retention of a rights-based approach is essential to ensure against infringements by the majority, who heretofore have offered charity rather than surrendered control to the person with impairment and her allies.¹³ The receipt of charity, by definition dependent on the beneficence and pity of others, will never lead to the primary good of respect. Is it possible to transform a rights-for-duties model, wherein people *consciously* undertake duties, into a rights-for-contribution model, wherein extra-rational action that benefits society satisfies the criterion? Could a shift in perception of value open areas of participation heretofore closed to people with severe cognitive impairment? This work will reevaluate the importance of considering the needs of people with cognitive

¹³ The author acknowledges the existence of impairment, so severe as to preclude the ability to self determine, but insists that in these cases, power over policy should reside in allies who have intimate knowledge of the individual with impairment’s best interests and this will be discussed in detail in the summary chapter of this work.

impairment in any original design and will focus on a reworking of Rawls's *justice as fairness* in order to preserve a rights-based model, inclusive of the useful thought experiment referred to as the *veil of ignorance*.

Rawls is concerned that Kant's *categorical imperative*, a version of the golden rule, be assured and uses a mechanism, which eliminates a social designer's individual desires and prejudices. Just as Lady Justice wears a blindfold, Rawls's designers enter into consideration of what a just society must be founded on, a state known as the *original position*, under theoretical constraints. Rawls's designers possess two *moral powers*, reasonableness and rationality, and are blinded in part by the veil of ignorance.

The idea of the original position is to set up a fair procedure so that any principles agreed to will be just. The aim is to use the notion of pure procedural justice as a basis for theory.¹⁴ Somehow we must nullify the effects of specific contingencies which put men at odds and tempt them to exploit social and natural circumstances to their own advantage. Now in order to do this I assume that the parties are situated behind a veil of ignorance. They do not know how the various alternatives will affect their own particular case and they are obliged to evaluate principles solely on the basis of general considerations.

It is assumed, then, that the parties do not know certain kinds of particular facts. First of all, no one knows his place in society, his class position or social status; nor does he know his fortune in the distribution of natural assets and abilities, his intelligence and strength, and the like. Nor, again, does anyone know his conception of the good, the particulars of his rational plan of life, or even the special features of his psychology such as his aversion to risk or liability to optimism or pessimism. More than this, I assume that the parties do not know the particular circumstances of their own society. That is, they do not know its economic or political situation, or the level of

¹⁴ Pure procedural justice refers to the notion that if the procedure under which principles are designed is just, the succeeding principles will also be just.

civilization and culture it has been able to achieve. The persons in the original position have no information as to which generation they belong.¹⁵

Though he himself does not mandate any particular outcome, Rawls believes that designers will formulate two guiding *principles of justice* under the veil, which will constitute the rules under which legislators will construct the foundations of law. Rawls describes the first principle: “Each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all.” Rawls calls this the *principle of equal liberty*. He continues with the second principle:

Social and economic inequalities are to be arranged so that they are both: a) to the greatest benefit of the least advantaged, consistent with the just savings principle, and b) attached to offices and positions open to all under conditions of fair equality of opportunity.¹⁶

This, Rawls refers to as the *difference principle*. As compelling as Rawls’s justice as fairness is and as inclusive of most of humanity, the goal of this work is to refashion several components to expand its scope to cover all people and discover a system of complete democracy.

The author would argue that a third principle of justice must be included to assure true democratic outcomes. The third principle states: *All structures arising from the first two principles must be open to all human beings—fully inclusive—without exception.*

The author expects that this third principle will be embraced by the reasonable and rational designers because it is in their self-interest to do so. The concept of self-

¹⁵ John Rawls, *A Theory of Justice: Revised Edition* (Cambridge, Massachusetts: The Belknap Press of the Harvard University Press, 1999), 118.

¹⁶ John Rawls, *A Theory of Justice*, 266. The “just savings principle” governs the consumption of goods with sustainability and even growth of these for future generations in mind.

interest—that interest, which might sway a person’s choices toward personally favorable outcomes—is seen, by this author, as inclusive of favorable outcomes for all people with whom the designer self-identifies. Arenas of self-interest expand past the boundaries of an individual’s actual person and past the confines of time, to encompass others, including one’s future self, whose well-being is of such importance to the designer as to define her own well-being.

Rawls means to assure a form of empathetic behavior when he constructs the veil. In the original position, because the designer is veiled from all of his individual characteristics, Rawls forces consideration of the circumstances of every possible person the designer could be. The designer must consider those of all possible ethnicities, cultures, genders, classes, income brackets, endowments, and other individual characteristics. Yet, the veil can never hide from the designer the fact that she can reason, and, if the designer were to make choices based on a narrow version of self-interest, the circumstances of people with cognitive impairment might remain unconsidered. Yet people actually act within a broader definition of self-interest. The veiled designer cannot know if impairment affects his child or others with whom he identifies, nor can he know, given the nature of impairment, whether he will become impaired imminently or in the future. The unpredictable and non-discriminating nature of impairment means that its lack of consideration in the original position will expose participants, who all have impairment in a potential state, to the consequences of policy, which fails to address circumstances that might define any human future. Within an expanded notion of self-interest, the circumstances of people with severe cognitive and physical impairment will be represented because, among many reasons, it is personally

advantageous for participants to do so. Yet, without the inclusion of people with cognitive impairment in the model—if they are held apart and deemed anomalies—how will consideration of their circumstances enter the consciousness of the designers?

The social relevance of people with cognitive impairment, the author will argue, highlights the need for a theoretical restructuring of concepts of contribution and value, beyond rationality, that would lead to a reconceived notion of rights-bearing status and positions of respect. Can theory redefine personhood in a non-traditional way that can, but need not, include the ability to make moral choices, in order to extend value to previously excluded individuals, who nonetheless benefit society through extra-rational contribution? It seems essential to the author to explore the contribution and subsequent value to society of people with cognitive impairment (and all impairment, for that matter). Notions of value should not be confused with ideas of intrinsic human worth. Acceptance of the latter does not lead an individual seeking community based on mutual advantage to court the participation of a non-contributor. Only social valuing can uproot the entrenched notion of worthlessness inherent in terms like “useless eaters.”

Yet, changing recalcitrant understandings is far from easy. Problematic perceptions not only involve notions of value, they also involve notions of what constitutes life with impairment. In the author’s experience, most people without impairment do not understand the experience and have vast misunderstandings and deeply rooted prejudices. The author will endeavor to explore these misunderstandings in depth in an effort to reveal the truth, as experienced by those who live with impairment and the disability created by society’s ill-conceived “othering.” Without social familiarity and the attendant awareness of everyone’s potential for impairment, even a

new, maximally comprehensive and inclusionary model of Rawlsian democracy will not succeed. Before embarking on this journey, which will conclude with a rethinking of Rawls, it seems necessary to address questions surrounding whether basic Rawlsian theoretical tenets are valid. The author has not infrequently been asked to defend the two discussed below and if he cannot satisfactorily address these concerns, using justice as fairness as a foundation is doomed before the project is undertaken.

If one questions whether a Rawlsian system of justice including an original position can actually exist, the author believes that it can—not just as a standpoint from which original designers determine the principles that will guide society’s development, but as an ongoing perspective, which if assumed will encourage just outcomes in all decisions that have an impact on the governance of society. If one questions whether a social contract can actually exist, the author believes that it can as well. Rawls is setting forth a construct that, if employed by social designers, maximizes the potential for justice within society. He is calling for people to assume the *perspective* of the original position as they create and then adhere to, or challenge, the *basic principles* of a community or the interpretation of these principles.¹⁷ Unlike earlier contract theorists, Rawls focuses beyond an anthropological origin of justice and constructs what is capable of becoming an ongoing ideal viewpoint from which individuals can participate in the formulation of just decisions. Each time the author participates in political organizing, votes, pays taxes without cheating, follows the law, or accepts the consequences of breaking the law, he affirms his participation in the contract. If he chooses to accept the basic tenets of his society (a constitution) or chooses to participate lawfully in changing those tenets, he

¹⁷ John Rawls, *A Theory of Justice*, 120.

affirms the contract. Each time he votes to fund services for people with cognitive impairment, to assure equal pay for women, or to allow same-sex marriage, he votes with the veil of ignorance as a perspective. The veiled perspective Rawls outlines encourages a moral thought process based on identification with each and every member of society.

If one questions whether humans are actually risk-averse, an important assumption in accepting the value of the original position, the author argues that there is a difference between being risk-averse when choices can be reversed or losses, due to choices, recouped, and when, as is the case in the original position, choices have consequences that are irreversible without revolutionary activity. In the original position, one is deciding fundamental rights, opportunities, and social foundations for society.

Even if one knew in the *original position* that the citizen one represents enjoys risk-taking, this would still not be a reason to gamble with his or her rights, opportunities, and starting position in society; for if she were born into a traditional, repressive, or fundamentalist society, she might well have little opportunity for risk-taking, gambling, entrepreneurship, and the like. It is rational then even for the risk-taker to choose conservatively in the *original position* and guarantee her future opportunities to take risks. (And assuming that the parties are trustees, then it would be not simply irrational but a dereliction of duty to choose otherwise.)¹⁸

Even if one accepts the possibility of a veil of ignorance, sees the merits of making decisions from the perspective of the original position, and accepts that from such a foundational position, designers would be risk averse, it is impossible to deny that justice as fairness, as it stands, continues in the tradition of previous moral theories requiring rationality for participation and implementation and the exclusionary outcome

¹⁸ Samuel Freeman, "Original position," *The Stanford Encyclopedia of Philosophy*, last modified Dec. 20, 2008, <http://plato.stanford.edu/entries/original-position/>

of that criterion. Rawls describes his participants as “free and equal...fully cooperating members of society over a complete life...”¹⁹ As a consequence of the relationship between cooperation and intent, this description of participants excludes people lacking rationality. In *Political Liberalism*, Rawls acknowledges that justice as fairness, as it stands, “may fail” to deliver justice to people with severe cognitive impairment. He continues, “How deep a fault this is must wait until the case itself can be examined.”²⁰

The intent of this work, then, is to revisit Rawls’s justice as fairness in light of intervening decades of disability consciousness and the emergence of competing theoretical constructs pertinent to the lives of people with impairment, specifically to those with an inability to reason or reason fully, and determine whether new perspectives can expand its scope into a more comprehensive model. By marrying Kantian confidence in the human potential for self-examination, creative choice, and a desire for the justice, fairness, and freedom fostered by an ethic of reciprocity with the social contract perspective of individual voices finding common ground and designing a society inclusive of mutually beneficial structures, Rawls successfully challenged the predominance of utilitarian theory in the post-Enlightenment era. He resurrected the relevance of the unique thinker, as opposed to a statistical individual, and this thinker’s reasoned contribution to the construction of a model, which leads to social justice. His brilliant effort provides a model for democracy, which deserves reconsideration, as Rawls himself anticipated. Heretofore, the incompatibility of an inability to reason and self-determination, the historically acknowledged nature of contribution as singularly reason-

¹⁹ John Rawls, *Political Liberalism*, 3.

²⁰ John Rawls, *Political Liberalism*, 21.

based, as well as the question of rights-claiming for people with severe cognitive impairment have encouraged contemporary theorists, in their attempts to amend perceived exclusionary deficits in Rawls, to abandon a “rights-for-duties” model. Proposed theories, inclusive of people with impairment have been offered by care theory philosophers and proponents of the capabilities approach. The author seeks to investigate and understand these perspectives and discover potentially beneficial material, but his work will endeavor to preserve a procedural framework, which possesses the authenticity and authority inherent in a social design that incorporates the participation of each member in society, and to argue the benefits of a theory predicated on rights and the essential redress they afford the most vulnerable. The author will also interrogate contemporary utilitarian theory, especially as envisioned by Peter Singer, both for its interest in impairment and for its provocative misunderstandings, which heavily contribute to injustice.

While justice as fairness provides a foundational respect for humans essential to an inclusive theory, changes, and at times incorporation of Rawls’s underemphasized understandings, will need to take place. The author views Rawls’s focus on David Hume’s circumstances of justice as exclusionary and he will introduce possibilities for participation, beyond the constraints of rough equality. He seeks to replace a notion of personhood, based on autonomy and rationality, which Rawls attributes to Kantian influence in section forty of *A Theory of Justice*, with a highly social conception of participation derived from Rawls’s later discussions of social unions. The concept of social unions allows for individuals to contribute their strengths and abilities to the community and for the community to make resources available to its members, which

they individually lack. Some contributions will involve the production of great ideas, debate, and innovation while other contributions will involve the demonstration of empathy and caring. The provision of a reality check on issues of corporeal fragility and the intrinsic human need for care will also be understood as contributory. The author will clarify ways in which people with severe cognitive impairment and the injustices they encounter illuminate the unresolved imperfections of society and provide a catalyst for the work of elimination of still-existent faulty structures of hierarchy that will lead to a more mature and just society. He will also investigate opportunities for social development available to those in society who engage in the challenges of building community inclusive of individuals with severe impairment and explore ways in which the disability community illuminates important aspects of what it is to be truly human.

This work will challenge theorists to justify why contribution, made possible through rational acts, has received exclusive acknowledgement, while relational contribution elicits a more dismissive response. Theorists must acknowledge that without relationship, humans lack context and thus, self-definition. Being a party to the social contract, or any other social construct, requires choosing relationship. Relationship can certainly engage reason, but it can also encompass affective bonds and the thought and action ignited by those bonds. When an individual, with whom allies share strong bonds, encounters social barriers that deny freedom and happiness, and when removal of those barriers challenges society's status quo on a daily basis, advocates and self-advocates find their identities conflated with the quest for justice. They become more engaged, more thoughtful, and more aware—in other words more human. Another characteristic of being human involves living inside a vessel, which is subject to entropy and disease—

injury and imperfection. Historically, society has sequestered those who provide reminders of the frailty of the human body and mind, and in so doing has doggedly clung to a chosen, comfortable illusion. What has been lost in this collective behavior is the opportunity to lead truly authentic lives, to embrace and incorporate the complete human experience. People with impairment can lead us in claiming our full humanity and in so doing make an invaluable contribution.

Chapter Two

Investigation of Theories that Consider People with Severe Cognitive Impairment

Care Theory

Can I translate myself to you?

Do I need to?

Do I want to?

*When I say **crip** I mean flesh-proof power, flash mob sticks and wheels in busy intersections, model mock.*

*When I say **disability** I mean all the brilliant ways we get through the planned fractures of the world.*

*When I say **living in America today** I mean thriving and unwelcome, the irony of the only possible time and place.*

*When I say **cure** I mean erase. I mean eradicate the miracle of error.*

*When I say **safe** I mean no pill, no certified agency, no danger to myself court order, no supervisory setting, no nurse, can protect or defend or save me, if you deny me power.*

*When I say **public transportation** I mean we all pay, we all ride, we all wait. As long as necessary.*

*When I say **basic rights** I mean difficult curries, a fancy-knotted scarf, a vegetable garden. I mean picking up a friend at the airport. I mean two blocks or a continent with switches or sensors or lightweight titanium, well-maintained and fully-funded. I mean shut up about charity, the GNP, pulling my own weight, and measuring my*

carbon footprint. I mean only embrace guaranteed can deliver real equality.

*When I say **high-quality personal assistance services** I mean her sure hands earning honorably, and me eating and shitting without anyone's permission.*

*When I say **nondisabled** I mean all your precious tricks.*

*When I say **nondisabled privilege** I mean members-only thought processes, and the violence of stairs.*

*By **dancing** I mean of course dancing. We dance without coordination or hearing, because music wells through walls. You're invited, but don't do us any favors.*

*When I say **sexy** I mean our beautiful crip bodies, broken or bent, and whole. I mean drooling from habit and lust. I mean slow, slow.*

*When I say **family** I mean all the ways we need each other, beyond your hardening itch and paternal property rights, our encumbering love and ripping losses. I mean everything ripples.*

*When I say **normal** I don't really mean anything.*

*When I say **sunset, rich cheese, promise, breeze, or iambic pentameter**, I mean exactly the same things you mean.*

*Or, when I say **sunset** I mean swirling orange nightmare. When I say **rich cheese** I mean the best food I can still eat, or else I mean poverty and cholesterol. When I say **promise** I mean my survival depends on crossed digits. When I say **breeze** I mean finally requited desire. When I say **iambic pentameter**, I mean my heart's own nameless rhythm.*

*When I say **tell the truth** I mean complicate. Cry when it's no longer funny.*

*When I say **crip solidarity** I mean the grad school exam and the invisible man. I mean signed executive meetings, fighting for every SSI cent.*

*When I say **challenges to crip solidarity** I mean the colors missing from grant applications, the songs absent from laws. I mean that for all my complaints and victories, I am still sometimes more white than crip.*

When I say anything I know the risk: You will accuse me of courage. I know your language all too well, steeped in its

*syntax of overcoming adversity and limited resources.
When I say courage I mean you sitting next to me, talking,
both of us refusing to compare or hate ourselves.
When I say **ally** I mean I'll get back to you. And you better
be there.*—Laura Hershey, “Translating the Crip”

What do current theorists, who work at the intersection of theory and impairment, offer? Which new concepts are useful and which are detrimental? Beginning in 1982, Carol Gilligan explored a dichotomy between the moral development of boys and girls. In *In a Different Voice*, she posits that gender identity, formed before a child turns three years old, is established differently for girls than it is for boys. Primary caregiver parents, being mostly female, experience their girl children in a same-as-self way, while experiencing their male children as gender opposite. Thus, while boys must pull away from their mothers in order to develop their masculine personas, girls have no need to separate in developing their gender identity. Girls often grow to become most comfortable with attachment and close social bonding, while boys often identify with autonomous, independent behaviors. For future problem solving, boys will rely on impersonal, abstract principles (the golden rule, justice, and democracy), while girls will make choices based on desired interpersonal outcomes (harmony, maintenance of relationship, and responsibility for each other).²¹

²¹ Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development* (Cambridge, Massachusetts: Harvard University Press, 1982), 7-8. By 1986, in a group discussion of *In a Different Voice* appearing in the journal *Signs*, Gilligan relaxes any previously espoused strict dichotomy in the development of females and males in favor of the notion that each gender has the potential for developing these perspectives, while maintaining that traditional liberal theory, in patriarchal tradition, fails to validate the importance of relationship in moral decision making.

Gilligan quotes the replies given by, first, a man and then a woman in response to questions asked by Lawrence Kohlberg in his research into the nature of moral problem solving. Kohlberg queried the twenty-five year old man on the meaning of morality. The man answered:

I think it is recognizing the right of the individual, the rights of other individuals, not interfering with those rights. Act as fairly as you would have them treat you. I think it is basically to preserve the human beings right to existence. I think that is the most important. Secondly, the human being's right to do as he pleases, again without interfering with somebody else's rights.

Kohlberg then asked the twenty-five year old woman if there is any absolute correct moral choice or "is everybody's opinion equally right." She answered:

No, I don't think everybody's opinion is equally right. I think that in some situations there may be opinions that are equally valid, and one could consciously adopt one of several courses of action. But there are other situations in which I think there are right and wrong answers, that sort of inhere in the nature of existence, of all individuals here who need to live with each other to live. We need to depend on each other, and hopefully it is not only a physical need but a need of fulfillment in ourselves, that a person's life is enriched by cooperating with other people and striving to live in harmony with everybody else, and to that end, there are right and wrong, there are things that promote that end and that move away from it, and in that way it is possible to choose in certain cases among different courses of action that obviously promote or harm that goal.²²

Gilligan goes on to cite many instances where male and female responses cleave along autonomy versus relationship and responsibility lines. Gilligan's construct of the relative importance of relationship in female choice-making spawned multiple investigations

²² Carol Gilligan, *In a Different Voice*, 19-20.

among feminist theorists in a myriad of fields dealing with the importance of relationship, as opposed to the singular importance of rationality in human, and especially feminine, motivation.

Feminist philosopher and care theorist, Eva Feder Kittay's statement that every person is "some mother's child" speaks to her understanding of the authority of human relationship as a basis for personhood (perhaps relational personhood is an appropriate term) and equality of standing. She speaks to the reality of identification with progeny without regard for intellectual capacity, and to a desire to acknowledge human commonality, regardless of degree of intellect. The author finds agreeable material within Kittay, while taking issue with other aspects of her theory.

While acknowledging rationality and autonomy as useful characteristics for participation in a moral community, she sees them as neither essential nor exclusive, stressing emotional connection instead.²³ Other human capacities critical to a moral community might be absent in some with both rationality and autonomy. Kittay uses the example of Nazi doctors to describe *persons* who not only fail to make a moral contribution, but manifest acts of evil incarnate, despite their rationality. She sees their behavior as devoid of important extra-rational traits including empathy, fellow feeling, and a capacity for and appreciation of kindness, harmony, and love.²⁴ She is, of course, right in this observation. Rawls, too, acknowledges that rationality alone fails to promote moral personhood and includes the property of being reasonable when delimiting this

²³ Eva Feder Kittay, "At the Margins," 122.

²⁴ Eva Feder Kittay, "At the Margins," 122-123.

status.²⁵ He would see the decisions of Nazi doctors as unable to be universalized and therefore unreasonable. It is likely that even those monsters—humans devoid of feeling when subjecting individuals from certain delineated groups to torture—went home and demonstrated fellow feeling, empathy, and kindness to their families and friends. They did not, however, demonstrate an interest in universalizing their actions. Unlike Kittay, Rawls does not invoke the emotional realm in his criteria for moral personhood. Acting *reasonably*, like rationally, is an intellectual and not emotional exercise. It is, nonetheless a *relational* exercise. Many, who dwell solely on the rational, self-interested aspect of choice making in Rawls, overlook the association between reasonableness and relationship. Self-interest, for Rawls, incorporates an interest in the well-being of the general other, as a healthy commons facilitates the flourishing of individual expression. Rawls is not dependent on reciprocal caring between specific individuals, a caring that is responsive and thus changeable and not assured. His theory survives individuals who lack empathy and altruism, and that is good as such people surely exist.

The author agrees that beneficial human traits, beyond rationality, exist and wonders if Kittay's *person* can find a place within a reconceived Rawlsian model. Kittay thinks not. Instead of reconceiving Rawls, she prefers to replace rationality with *dependence*, a natural, universal, human experience, as an alternative, more inclusive, descriptor of the human condition. The author will later elaborate on alternate solutions to Rawls's rationality problem because he finds many of Kittay's assumptions and their consequences troublesome for people with impairment. He would like to insist, in advance, that he is a feminist and acknowledges the interdependency of human beings.

²⁵ John Rawls, *A Theory of Justice*, 130.

Yet, for people living with severe impairment, the concept of dependence carries such a historical, political, and emotional charge that it is impossible to comfortably sit next to the word and act dispassionately. For the disability community, to be dependent is to be at the mercy of. To be dependent is to be powerless. The disability community has slowly and painfully dragged itself past notions of dependence into a place of agency and it is not going to willingly give ground. There seems to be a difference between the acknowledgement of humans as social animals and the interdependency of human existence, where periods of the same person's life might include both care-giving and the receipt of care, and finding any comfortable association with acceptance of life-long dependency with its attendant loss of power as a replacement for the concept of autonomous control over one's life wherever possible.

Kittay criticizes the liberal tradition where independence is "hypervalorized" for "stigmatizing" dependency and therefore relegating people with severe cognitive impairment to non-participant status. The author is not convinced that sidelining self-determination is the answer. Autonomy, to whatever degree possible, belongs in the first tier of goods. Until people have no desires, preferences, priorities, or volition, the expression of their wills requires the honoring of whatever autonomy is within their capability. People with severe cognitive impairment have their own individual authentic selves, and the full expressions of these are bound to society's recognition of their autonomy. Calculative rationality may be necessary for the understanding of long-term ends and the most advantageous means to achieve them, but a sort of rationality (it might be called preferential rationality) determines more immediate desires and choice making. Most humans possess this capacity. All have dependencies and interact in personal and

professional ways to address these through relationship, but the quality of these relationships relies upon respect for one another's autonomy. The author acknowledges that some people, at the farthest end of the rationality continuum, lack the ability to self-determine to any degree, but is most comfortable suspending this reality and approaching all people with a respect for their autonomy, to whatever degree possible, as a position that assures that erroneous assumptions never deny the possible.

Some care theorists, including Jennifer Nedelsky, criticize the liberal tradition as incapable of merging the role of the social with that of the rational, because the tradition assumes a "dichotomy between autonomy and the collectivity." According to Nedelsky, in mainstream liberal theory, one achieves autonomy "by erecting a wall (of rights) between the individual and those around him...the most perfectly autonomous man is thus the most perfectly isolated."²⁶ This author hastens to point out that individuals only invoke their "wall" of rights when others violate these rights. This state is not continuous, nor is it ubiquitous. If an individual asserts his right to equal protection and due process (under the 14th amendment) because he desires to testify at the state capitol, which lacks wheelchair accessibility, while he is suing the state, he nonetheless continues to go to work, visit with family and friends, and enjoy recreational activities. He does not live as a lone entity, isolated by his rights, but rather in a community, where social and political access depends upon the exercise of these rights. Would he be less isolated if he

²⁶ Jennifer Nedelsky, "Reconceiving Autonomy: Sources, Thoughts, and Possibilities," *Yale Journal of Law and Feminism* 1, no.1 (Spring 1999): 12. The author believes she is speaking here about people who can express their autonomy as vocal self-advocates, but can see her argument pertaining to anyone with any degree of autonomy.

was unable to lend his testimony to the creation of a bill, discuss his position with his representatives, or listen to the arguments of others?

The author wonders about Nedelsky's conflation of autonomy and isolation. He questions the nature of autonomy in isolation. It seems that autonomy, meaning, according to Webster, "functioning independently without control by others" lacks meaning without an external challenge. Furthermore, the exercise of rights promotes inclusion within society, not isolation. Trisha Fisher is an individual with cognitive impairment as the result of a brain injury sustained as an infant. In July of 2006, Fisher gave birth to a son at Exemplar Medical Center in Wheatridge, Colorado, and within hours, at the request of her guardian/parent, underwent a tubal ligation, which rendered her sterile. Though she signed a consent form, her position is that she believed she was consenting to an epidural to ease the pain of childbirth, not a sterilization procedure.²⁷ Fisher's former emergency guardian, aware that Fisher wanted more children, helped her bring a complaint, along with and through the Colorado Cross Disability Coalition doing business as Center for Rights of Parents with Disabilities' legal department, against the doctor, the doctor's practice, the hospital, and the corporation that owns the hospital.

The complaint contends that medical personnel had a duty to comply with the Colorado Developmental Disabilities Act prior to performing any sterilization procedure upon Fisher by obtaining her free and voluntary informed consent, which would require that a non-interested professional would explain and ensure her understandings of the

²⁷ Susan Greene, "Greene: It was a life-altering decision, but who made it?" *Denver Post Online* (Denver, CO), September 9, 2010, found at http://www.denverpost.com/ci_16027261?source=sb-facebook.

repercussions of the surgery. The lawsuit charges the defendants with failure to do so.²⁸

Though Fisher lost her complaint, its filing was essential to the ongoing fight against society's preconceived notions regarding the ability of persons with impairment to parent. Her decision to assert herself in the face of the belief that she was incapable, positioned her within an activist community, which assumes she is capable and autonomous until proven otherwise. This community includes rather than isolates her.

Another interesting aspect of this story is that Fisher's guardian/mother removed her son from Fisher after his birth and was in the process of raising him herself when Fisher successfully sued for emancipation and subsequently won custody of her child. She currently is engaged in raising her son herself with community supports.²⁹ Did Fisher erect a wall between herself and society by exercising her rights? Is she more isolated than she would have been if she had silently acquiesced to her mother's belief that she was unable to be a parent? She has community support in her parenting efforts and friends who have advocated with her for her autonomy. The author contends that she would be far more isolated within the limited, directed, and circumscribed world her mother had envisioned for her. While he sympathizes with the fears Fisher's mother suffered at the thought of the risks involved in Fisher's exercise of her autonomy, he encourages everyone who worries about a loved one with impairment to acknowledge the essential role risk-taking assumes in the ultimate growth and maturation of every human being.

²⁸ *Fisher, et al v. Crawford, Saunders, M.D., P.C., et al*, Case No.: 2008CV3702, a case brought before a Colorado court by the Colorado Cross Disability Coalition, d/b/a Center for Rights of Parents with Disabilities, found at <http://www.ccdonline.org/case/491>.

²⁹ Susan Greene. "Greene: It was a life-altering decision", found at http://www.denverpost.com/ci_16027261?source=sb-facebook.

Thomas E. Hill, Jr., Kenan Professor of Philosophy at the University of North Carolina, in concordance with the author, takes issue with the argument that autonomy is incompatible with human dependency—that self-determination requires isolation. In defense of his modified Kantian model of moral autonomy, he argues that social and relational behaviors, such as taking the needs of others into consideration when making important life decisions, do not assume one’s giving up self interest. Hill states that his version of autonomy, “does not assert, with Kant, that basic moral principles are grounded in pure reason, independent of all contingent features of human nature, that they admit no exceptions, or that they command only our wills and not our feelings.”³⁰ Autonomous action based on self-interest may involve accounting for one’s relationships with others and society as a whole. He states:

...accepting this right of autonomy does not mean that we must accept more extreme views that are sometimes associated with the word ‘autonomy.’ For example, we can acknowledge the right without in any way implying that self-sufficiency, independence, and separation from others are goals worth pursuing. Respecting people’s autonomy requires resisting the temptation to ‘take charge’ of their lives without their consent, but it does not deny anyone the choice to share with others, to acknowledge one’s dependency, to accept advice, or even to sacrifice for the interest of others.³¹

Theorists, such as Kittay and Nedelsky, who deny that the states of dependence and autonomy can coexist, unnecessarily sacrifice the rights and self-determination of those with severe impairment.

³⁰ Thomas E. Hill, “The Importance of Autonomy,” in Thomas E. Hill, *Autonomy and Self-Respect* (Cambridge, United Kingdom: Cambridge University Press, 1991), 47.

³¹ Thomas E. Hill, “Importance of Autonomy,” 49.

Rights, however, under current understanding, must always occur in the company of duties.³² For that reason, the rights of those who lack traits, which hold the potential for traditional contribution, are, at least from a classical theoretical standpoint, unclaimable. Yet, in order to live lives of dignity and fulfillment, people with severe cognitive impairment must have enforceable access to basic human goods. The answer lies in a shift in public and personal perceptions of value and contribution. With their integration, many previously marginalized groups have contributed their unique perspectives and processes and society has benefited from their contributions. This is not to say that integration came free from angst and without cost, but the enrichment of the community and its steady movement toward justice argue for its value.

Integration of people with severe cognitive impairment will require an expanded concept of contribution. Because the exercise of duty requires conscious choice, society must consider whether unconscious contribution might also confer rights-bearing status. If society is better for the presence of people with severe cognitive impairment, the experiences and perspectives of their parents, friends, and allies, the challenges they present, and the lessons they teach, is it conceivable that they contribute, even if they are unable to perform a duty? And, though people with impairment who can reason qualify as performers of duties, their contributions could be expanded if, instead of categorizing them as burdensome, society acknowledged the benefit of their full inclusion, and the access to their unique perspectives and processes that inclusion could provide. Both the unintended contributions made simply because a participant has a unique nature,

³² For a discussion of the frivolity with which American rights-discourse dismisses duties, see Mary Ann Glendon, *Rights Talk: The Impoverishment of Political Discourse* (New York, New York: The Free Press, a Division of MacMillan, Inc., 1991), chapter 4.

circumstance, and experience and the reasoned performance of duty demonstrated by the independent person with impairment offer heretofore-untapped riches.

As for the notion that no severely impaired individual can lay claim to independence, Kittay offends this author with her tone in a lecture delivered in San Francisco in 2004 at the Care Matters Symposium and later published with some emendation in conjunction with Bruce Jennings and Angela Wasunna. She states:

The clarion call of the disability rights movement that emerged in the early 1970's was the demand for 'independence,' resulting in the 'Independent Living Movement.' The idea behind this movement was that dependency of disabled people was socially constructed. People with impairment become disabled not by virtue of the intrinsic nature of the impairment but because of physical and social constructions that become a barrier to living independent lives. Yes, the activists and theoreticians of the movement concede, many people with impairment need assistance, but this does not constitute dependence. With assistance and control over the aid they receive, persons with impairment can live 'independent' lives.³³

The quotations around *independent*, interjected by Kittay, bespeak both her disdain for the position of the independent living community and a lack of understanding for the difference in experience between receiving care as the recipient of personal or societal charity and purchasing needed services. The difference between how it feels to be someone's charge (and often, burden) versus someone's employer is immense. The Independent Living Movement that Kittay derisively speaks of in the past tense is neither past nor some delusion. The author, for one, venerates the courage and fortitude of the

³³ Eva Feder Kittay, Bruce Jennings, and Angela Wasunna, "Dependency, Difference, and the Global Ethics of Longterm Care," *The Journal of Political Philosophy* 13, no. 4 (2005): 465.

early activists who redefined the landscape and made possible many aspects of his life that are dignified and powerful.

To those who would challenge the use of the word independent by those who purchase their independence with public monies, the author acknowledges that if independence equates with self-reliance, people who utilize public programs, such as Medicaid are not demonstrating full independence. But, under justice as fairness, the monies used by a society are not the property of Joe or Jane; they are the property of the commons, equally available to whoever requires them to maintain a position of equal liberty. These monies are not “given” to those who need care by the rest of society, they are the equal property of all, available for use when the exercise of equal liberty requires them.

Traditionally, social contractors have been expected to perform duties requiring rational contribution and often contribution in an economic sense. In justice as fairness, people with cognitive impairment and even all those with extraordinary needs, which require high economic expenditure, are excluded from the original position, on the grounds that they stand outside a rubric of mutual advantage. If, however, society accepts the notion that people who cannot make a rational and economic contribution, contribute in other meaningful and even essential ways, notions of the singular value of rationality and the income generation it affords, as a ticket to entitlement, rights, or the benefits of the social contract, cannot stand.

Kittay further asserts that the aforementioned independence of the employer with severe impairment comes at the price of the “invisibility” of the personal assistant. She asserts that the illusion of independence depends on the sacrifice of the careworker’s own

authentic self. She describes the careworker as only an instrument of the will of the employer.³⁴ Kittay refers to a former personal care assistant, now a professor of sociology at Rider University, Lynn May Rivas, who writes about the relationship between people with impairment and their personal care assistants. Rivas states:

...the transfer of authorship (inherent in being invisible) is a negative phenomenon even for those who consciously work to make it happen. To be made invisible is the first step toward being considered nonhuman, which is why making another person invisible often precedes treating them inhumanely. To use Marxist terms, invisibility is the most extreme form of alienation—the ultimate manifestation of self-estrangement.³⁵

The author does not see the job of personal care assistant as unique in its requirement of subsuming some portion of one's individual will in the fulfillment of one's job description. While he agrees that any employer benefits from drawing on the good ideas and creative solutions that might flow from the employee, the employer, particularly when it is her personal care in question, has the right to dictate job parameters based on personal preferences. Living in a society necessitates subsuming personal choice in certain situations, while allowing its full expression in others. The employer's expertise or tastes also dictate degrees of employee autonomy. The author does not envision having an opinion on how a personal care assistant would organize their workspace, while anticipating concerns if his personal care assistant insists on saving his soul. Kittay's daughter, Sesha, who, though she has severe cognitive

³⁴ Kittay, Jennings, and Wasunna, "Dependency, Difference, and Global Ethics", 466.

³⁵ Lynn May Rivas, "Invisible Labors: Caring for the Independent Person," in *Global Women: Nannies, Maids, and Sex Workers in the New Economy*, ed. Nancy Ehrenreich and Arlie Russell Hochschild (New York, New York: Henry Holt and Company, 2002), 79.

impairment, has a strong preference for classical music, particularly Beethoven, per Kittay, should not have to endure only country music simply because that is the preference of her personal care assistant.

Does an individual's desire to direct his or her life, to whatever degree possible, translate into Kittay's criticism that "invisibility" is a job requirement for his personal care assistant? This author thinks not. A caregiver's workday, like most people's workdays, mixes tasks and relational interface. If the author's personal care assistant is helping him get up in the morning, he does not expect silence, rather a conversation—interesting to both parties. Does he also expect the assistant to be on time so that he can empty his bladder before he is in pain, to dress him in the clothes he desires, or to prepare a breakfast of his choosing? Absolutely!

Would people with impairment, as Kittay charges, prefer assistants to be robots? If the author could compensate for his inability to walk or inefficient fine motor skills with robotics, he would be delighted to do so. If Kittay judges his perspective as evidence that he would require an employee to be an automaton, the author is nonplussed and sees no connection whatsoever. To conflate an interest in robotic assistance with an expectation that a human should act robotically is illogical. To judge a desire for independence, whether that independence reflects effective functioning or control of care, because such a choice must evidence a desire to submerge another's essence is unfair. If Kittay judges a desire for independence as uncooperative to the Acknowledgement of Dependency Project, be assured that the author is clear that he needs help to function. He nonetheless thinks of the relationship with his personal care assistant not as one of dependency and inequality, rather as one of interdependency (he needs a service, they

need a job) and equality, where his ability to pay for care and his caregivers' ability to do a good job of facilitating his independence result in an agreement between equals. The author feels that living with functional limitations must be a prerequisite for judging whether dependency and autonomy are incompatible. He believes that those with permanent impairment have a unique perspective on this subject, and that it is possible to treat an employee as an authentic other without losing one's own expression of independence.

If the reader will allow a transition from academic language to the vernacular of storytelling, the author offers a brief story by Mike Ervin, disability rights activist, prominent playwright, and contributor to *New Mobility* magazine. It should put to rest any concerns that personal care assistants, even those whose employers are fervent independent living advocates, are, by necessity, in danger of losing their authenticity:

We're riding in an Amtrak sleeper car. I'm eating crab cakes and drinking cognac. Chris, my attendant, eats prime rib. And it's all free because Amtrak screwed up big and I bitched up a storm.

We were trying to get to a wedding and the once-a-day train from Chicago to Indianapolis was cancelled and all passengers were transported to Indy on buses. Of course the buses were not accessible, so Chris and I were the only ones left behind.

I bitched until I practically frothed. The best solution from the Amtrak woman: put us on the soon departing City of New Orleans...

The cornfields roll by and Chris says, 'Remember that first time we took Amtrak?' We have traveled a lot of places since I hired Chris in 2000. He holds the record for most consecutive years of hauling my ass out of bed and wiping my butt. We've traveled around the United States, to Canada and Germany.

‘Remember?’ Chris says. ‘I just started working for you. You wanted me to moon Bush.’

Now I remember! It all rushes back—the passing trains, the once-in-a-lifetime opportunity, the tidal wave of regret...

Late summer, 2000. Chris and I are returning to Chicago from St. Louis. Out amidst the farmland, the train slows to a halt. An announcement says we’re stopped to allow another train to pass.

But the delay drags on. There’s a buzz among the passengers: It’s that damn Bush and Cheney. Of course! It was on the radio that morning. Bush/Cheney whistle-stop tour coming to Springfield.

That means, I say to my suddenly wound-up self, that any minute their train will shoot right past our window. I’m overcome by a subversive urge. I blurt out to Chris, ‘When Bush goes by, moon him!’

Chris looks at me with a combination of fear, pity, amusement, and even a little admiration. And there it is, a 19th-century train, Abe Lincoln funeral style. In 10 seconds, it’s gone. Chris doesn’t move.

And Bush and Cheney pass into and out of my life, unmooned....³⁶

Relationships between employer and personal care assistant might be as varied in character as relationships between any two human beings. It seems impossible, however, to imagine any two people who interface on such intimate terms maintaining a completely impersonal, robotic relationship. The author offers another Ervin masterpiece: The columnist opens his article with a quote that epitomizes how many in

³⁶ Mike Ervin, “Train of Regret,” *New Mobility* 20, no. 194 (Nov. 2009): 40.

society construe the need for assistance inherent in situations of severe impairment and then offers his perspective:

Pain is not the main reason we want to die. It's the indignity. It's the inability to get out of bed or get onto the toilet, let alone drive a car or go shopping without another's help...Every client I've talked to...they've had enough when they can't go to the bathroom by themselves. Most of them say 'I can't stand my mother—my husband—wiping my butt.' People have their pride.

*--Janet Good, Founder,
Michigan Hemlock Society*

Ervin responds:

With apologies to whoever wrote the biblical Beatitudes, I'd like to offer a friendly amendment: Blessed are the butt-wipers.

Having said that, let me now attempt to break the silence on a topic that has been taboo for far too long. I can't wipe my own butt. There! I said it! And furthermore, I haven't been able to wipe my own butt for 20-some-odd years now. And every day over all those years I've always figured out a way to get it done. Some would be surprised to know that I still manage to lead a pretty fun life...

In fact there is often a very special kinship between wiper and wipee. It can be quite spiritual. It's hard to describe. But for those of you who haven't experienced it, there's an experiment you can conduct that simulates the feeling.

First make a list of the close friends and family in your life. Now make a list of the close friends and family in your life you could call upon if you suddenly needed to have your butt wiped (the same applies for bowel programs). The second list sure is shorter than the first, isn't it? It is with those folks on the second list that you share something deeper. The longer the list, the richer you are.

I have a friend like that. Her name is Carolyn. We've been buddies for a long, long time. And one of my fondest

memories of her was the time I drove my wheelchair through some doggie refuse. It got all in the ridges of my tires and she had to scrub and scrape and scrub and scrape. At one point she interrupted my repeated apologies by saying, 'Hey, shit is a part of life.'

That's what I mean. That's the kinship. I almost proposed to her then and there. Carolyn is definitely on my list of people I could call in the event of a butt-wiping emergency, and I hope I have earned a place on hers...³⁷

The author fails to see any compelling argument in the concern for the visibility of his personal care assistants that would justify any diminution of his autonomy. There are despotic employers in all work arenas and there are those who acknowledge the humanity, talents, and needs of their employees. This is not a unique artifact of work as a personal care assistant and therefore not a reason to wholly redefine the foundations of ethical theory.

In another instance of particularizing, with which the author disagrees, Kittay criticizes the liberal tradition for universalizing moral duty. The author assumes she is challenging the categorical imperative and its fellow notions of moral reciprocity, including Rawls's insistence on reasonableness as a moral power derived from utilization of the veil. She states:

Just as the selves of dependency relationships are not the selves of contracting parties, neither can ties between a dependency worker and her charge be represented as contractual relations. Ties of affection and concern bind the dependency worker and her charge. The ties are not between generalizable others, but between non-fungible, concrete others. The relations and moral obligations between the parties are not the general obligations we bear

³⁷ Mike Ervin, "Blessed are the Butt-Wipers," *New Mobility* 8, no. 47 (Aug. 1997): 52.

to another person, whoever they may be, but special relations.³⁸

The author wonders why any particular relations would require a departure from one's standard application of duty. Whether one's relational partner is unable to reciprocate seems irrelevant to one's own behavior. If one establishes a relational code toward others, based on how one would like to be treated, it would most likely include interaction based on respect, consideration, kindness, patience, and, very importantly, without condescension. What qualities does a person with a severe cognitive impairment possess that demand a deviation from that general code? The golden rule states, "Do unto others as you would have others do unto you." It does not say, "Do unto Joe as you would have Joe do unto you." The author likes the Hillelian version of the notion best for describing his perspective. Rabbi Hillel says, "That which is hateful to you, do not do to your fellow."³⁹ This perspective requires only that one knows her own desires in order to demonstrate moral treatment toward others. It does not suggest that if one's relational partner cannot reciprocate, one need not heed the directive. If the ethic of reciprocity changed depending on whom one was interacting with, one could not behave morally with others until one intimately knew each one's likes and dislikes. It would be impossible to interface appropriately with any but one's most intimate fellows. Is it ever moral to judge another's ability to understand or act consciously? The author thinks not and is most comfortable with suspending assumptions and basing his behavior on the

³⁸ Eva Feder Kittay, *Love's Labor: Essays on Women, Equality, and Dependency* (New York, New York: Routledge Press, 1998), 53.

³⁹ b. Shab. 31a.

possibility that he and the other have more in common than they do not. Even if the other is severely cognitively impaired, behavior based on an assumption of inequality contains the potential for causing harm, if not to the person with impairment, then to that person's loved ones who experience pain when others fail to demonstrate respect for the value of their friend or family member.

Care theory acknowledges extra-economic value in the social bonding generated by the dependent relationship, but does not sufficiently emphasize the contribution of the individual with impairment. Though Kittay finds value in the creation of connections fostered by dependent relationships, she stresses the contribution of the caregiver and caring in general. She is concerned with society's responsibilities to the caregiver, especially where a cared-for individual is so impaired as to, in her estimation, render reciprocation impossible.⁴⁰ She becomes more concerned for the careworker the more the relationship "diverges from relations among equals."⁴¹ The thrust of her argument focuses on the relative diminution of reciprocity available from the cared-for individual as his or her intelligence decreases. Kittay seems to value people like her daughter, Sesha, not for the contribution they make to society, but solely because they are a part of the human family—part of the dependency cooperative. The author fails to understand this position, especially in Kittay's case, as she describes many instances of beneficial interaction with her daughter and believes that even those with little ability to reason often empathize with their caregivers and loved ones.⁴² She describes her daughter:

⁴⁰ Eva Feder Kittay, *Love's Labor*, xiii.

⁴¹ Eva Feder Kittay, *Love's Labor*, xiii.

...Sesha's loveliness is not (only) skin deep. How to speak of it? The capacity for joy. The babbling-brook laughter at a musical joke. The starry eyed faraway look as she listens to Elvis crooning "Love Me Tender," the excitement of her entire soul as the voices blare out "Alle Menschen werden Bruder" in the choral ode of Beethoven's Ninth Symphony, and the pleasure of bestowing her kisses and receiving the caresses in turn. All variations and gradations of joy. Spinoza characterized joy as the increase in our power of self preservation and by that standard, Sesha's is a very well-preserved self. Yet she is so limited. She cannot speak. She cannot even say 'Mama'—though sometimes we think she says 'Aylu' (our translation, 'I love you').⁴³

Kittay clearly includes relational properties as qualification for personhood and attributes such properties to people with severe cognitive impairment, while ignoring that these relational abilities constitute contribution. The author insists that individuals with severe cognitive impairment positively affect those in direct relationship with them, while also often having a wider impact. Kittay's scholarship has clearly integrated her experience with Sesha into her academic worldview. The relationship has informed her thinking and no doubt enriched the pool of experience through which she is attracted to and works on philosophical problems. Kittay's work carries this enrichment to many others.

The author feels withered by Kittay's focus on Sesha's deficits. He worries that all of Sesha's vibrancy is made pale in comparison to her dependence. If dependence is accepted as the defining descriptor of what it is to be human, as care theorists would prefer, the author fears that autonomy, and the self-respect it engenders, will cease to be considered as a worthy goal. The author knows that each and every person is to some

⁴² Eva Feder Kittay, *Love's Labor*, 151, 166, 172.

⁴³ Eva Feder Kittay, *Love's Labor*, 151.

degree dependent every day of their lives and during some episodes, profoundly so, but, in the case of people with severe impairment, just as in the case of those without, autonomy must be pursued. Furthermore, he is hesitant to assume the inevitability of uninterrupted dependence for people born with severe impairment, when there is evidence that underestimation of ability leaves many unschooled in self-determining skills. Henry McCarthy, PhD, professor of rehabilitation counseling at Louisiana State University, writes about the dangers of underestimating the potential of people with severe intellectual impairment that inevitably lead to failure in the workplace and a subsequent lack of autonomy:

Our potential for employment is seeded and nurtured from early childhood experiences that seem merely to be the pragmatic requirements of immediate situations, but which cumulatively teach us to follow instructions, accept feedback, cooperate with peers, and stick to a task. Such early work socialization begins the development of two ingredients essential for eventual employment: *generic work skills and self-concept as a capable person*. As previously noted, these are in large measure shaped by the environments, expectations, and experiences to which we are exposed by family, teachers, and friends. Unfortunately, many youths with disabilities have been controlled by agents of socialization whose well-meaning but defeating psychological influence stunted the development of their work skills and self-concepts.⁴⁴ Despite these impediments, many individuals, often with the help of others in the disability community, have grown beyond their early, formative, restricted self-concepts to demonstrate the power of self-advocacy. Philosopher Bernard Williams states, ‘Oppressed human groups come of age in the search for emancipation when they speak for

⁴⁴ Henry McCarthy, “Attitudes That Affect Employment Opportunities for Persons with Disabilities,” in *Attitudes Toward Persons with Disabilities*, ed. Harold E. Yuker (New York, New York: Springer Publishing Company, 1988), 253-254.

themselves, and no longer through reforming members of the oppressive group...⁴⁵

The disability rights movement has sought to change a public mindset, which produced isolation and poor self-concept into one that fosters inclusion and maximization of autonomy. This has involved reformers within the non-impaired community as well as people with impairment themselves. One such reformer is William Bronston, M.D., who worked as a physician at Willowbrook State School, situated on Staten Island, New York, beginning in 1970. Bronston determined to bring down the system, which he considered to be a perpetrator of “crimes against humanity.”⁴⁶ Robert F. Kennedy described the Willowbrook wards as, “less comfortable and cheerful than the cages in which we put animals in a zoo.”⁴⁷ Bronston describes Willowbrook:

A resident at Willowbrook was statistically more likely to be assaulted, raped, or murdered than in any other neighborhood in New York City... I had never seen anything like it. I just stood there and tears welled up in me. I'd never seen such squalor. The wards were all concrete, with no furniture, nothing to soften the sound. There was a day room in each ward that was a big terrazzo-floored place with these wooden chairs and benches that were too heavy to lift. There were also some fiberglass chairs but those would constantly fly, people would throw them around. It was absolutely like something out of Dante's *Inferno*. These were wretched 'shades' in every form of disrepair, misery, withdrawal.

At first you don't get the full magnitude of it. It takes you day after day to fathom this hell. No programming going

⁴⁵ Bernard Williams, “The Human Prejudice,” in *Peter Singer Under Fire: The Moral Iconoclast Faces His Critics*, ed. Jeffrey A. Schaler (Peru, Illinois: Carus Publishing Company, 2009), 84.

⁴⁶ William Bronston, “Institutions: Part 4” in *What We Have Done: An Oral History of the Disability Rights Movement*, ed. Fred Pelka (Amherst, Massachusetts: University of Massachusetts, 2012), 317.

⁴⁷ William Bronston, “Institutions: Part 3” in *What We Have Done: An Oral History of the Disability Rights Movement*, ed. Fred Pelka (Amherst, Massachusetts: University of Massachusetts, 2012), 175.

on, the most token schooling happening, no support of continuity for the schooling. The minute the kid reaches beyond school age, they go deeper into the institution. No school, no future, no exit. They've got to die to get out...

The place was rampant with tropical diseases, some of which had been instilled purposely for study purposes, like inoculating kids with Hepatitis A in order to study how to develop a hepatitis vaccine. They also had every kind of intestinal parasite that you only see in the center of Africa...

The place smells like excrement all the time. Or this incredible sickening odor of Pine-Sol disinfectant, which comes in industrial cans of twenty, thirty, fifty gallons. It's mopped out on the floor by the inmates because there aren't enough staff to clean the place.

The place operates just a cellophane's width above absolute chaos. Shrieking, physical outbursts, people struggling against the imposition of the tranquilizing drugs that are car-loaded into them. Any excess movement, any resistance, any human anything is immediately met with a two hundred or three hundred milligram shot of Thorazine to knock them out.

The only heat in the place comes from radiators that are built into the walls with metal sheets in front of them. People get their drugs, which they are forced to take... Then they ...drag themselves over to the radiators, and fall asleep in heaps against and in front of them. So they're laying on the floor, which has this veneer of caustic, chemical disinfectant that's not being cut or diluted, this thick, gummy, slimy film, and it eats away at the residents' skin, so that they have these huge swaths of terrible rashes and psoriatic-kinds of crusts on them. They have burns on them because they fall asleep against the radiator, because they are drugged out...

I had a situation where I had a number of people with extremity amputations in their thirties. What was happening... was that these people were developing these incredible fungal infections from the athlete's foot that was just on the floor everywhere, coupled with the erosion of their skin from the caustic detergents used on the

floors...They would develop cellulitis of their feet and legs and then superficial vein thrombosis and then deep vein thrombosis, until the leg was destroyed within a decade from being in these buildings.

They had a disease that they called ‘Mongoloid Dermatitis,’ which was supposed to be some kind of strange skin disease associated with Down syndrome. This stuff would cause this heaped-up, intertriginous rash, like the spaces in between your fingers and on your chest and legs and shoulders, these scaly, terrible, psoriatic kind of crusts and rashes...Thousands of people in Willowbrook had been treated improperly for years by professional dermatological specialists who never made the diagnosis that the problem was environmental infestation with skin mites...

...What I did find out, little by little, was that there was a whole economic, big money aspect to what the hell was going on. That the institution at Willowbrook, that institutions in general, were major economic centers that hired thousands of people, purchased millions of dollars’ worth of stuff, paid very handsome salaries to the concentration camp managers. That these were all ‘professionals’ who had to be properly ideologized in order to be complicit with this scheme and believe that they were doing ‘good,’ to operate in compliance with policies of deprivation and reduction of resources...There was just wretchedness. Wretchedness and suffering and insanity and inhumanity. Short of Dachau, or a concentration camp in Germany where they were actually burning people every day—they didn’t have to burn people here. They needed to keep them alive because they needed to make money off them.⁴⁸

Bronston and other courageous reformers ultimately did cause the disintegration of the institutional system by leaking information to journalists and inviting them on unsanctioned tours of the abysmal facilities. The journalists, in turn, unveiled the

⁴⁸ William Bronston, “Institutions: Part 3” in *What We Have Done: An Oral History of the Disability Rights Movement*, ed. Fred Pelka (Amherst, Massachusetts: University of Massachusetts, 2012), 175, 176, 177, 178, 179, 180.

conditions to the outer public. Parents and parent groups, who had been encouraged to disengage from their children, to leave them in institutional hands and resume their lives and who, therefore, had been unaware of the conditions under which their children had been kept, joined the project. The breakdown of accepted, established and profitable institutions required massive advocacy, but by the middle of the 1970s, institutions were giving way to community living projects. Former residents of institutions were moved into group and foster homes and while the exodus marked the end of an intolerable past, it was not without traumatic aspects.

Another reformer, Dennis Heath, a trained minister and social worker worked within Fairview Training Center, an institution in Salem, Oregon, in the early 1970s. When the residents began to move into the community, he became a field-worker, who established outreach to observe and assist with the transition process. Heath initiated group meetings for the former residents. In the institutions Heath remembers the residents who were ready to go into the community still asking the staff for guidance on every tiny aspect of their activities. Once they moved out of the institutions, Heath invited them to group meetings to work out the problems they were encountering in integrating into society. His goal was to “help them learn how to be more powerful in and of themselves. They could run the group, they could choose what they wanted to talk about, and they could ask each other for opinions.”⁴⁹ Heath was invited to facilitate the participation of several of the group members in a convention hosted by the ARC. It was to be run by the “retarded” themselves. Heath describes the conference:

⁴⁹ Dennis Heath. “Self-Advocates,” in *What We Have Done: An Oral History of the Disability Rights Movement*, ed. Fred Pelka (Amherst, Massachusetts: University of Massachusetts, 2012), 326.

...during the two-day event, not one identified person, not one—as they called them in those days ‘mentally retarded person’—said anything. The teachers, parents, the ARC members, they did all the talking and the ‘mentally retarded’ people sat and rocked and looked at each other.

...we broke out into little clusters, into little groups that talked...And I asked, ‘How come none of you have gotten up and said anything?...I read the brochure and it said people from group homes, and wherever you were from, were going to run this convention.’ And this one guy laughed and he said, ‘Well, you can see how much we’re running it.’ And since it was billed as from the Association for Retarded Citizens, I said, ‘What do you all think of the name ‘retarded’?’ And there was like a unison of people who said, ‘We hate that name! We hate that!’ And I said, ‘Have you ever told anybody? Have you ever said anything?’

...when the session was over the people went out into the general meeting. And a teacher said, ‘Well, I’ll summarize’ what happened in our little group, and I said, ‘Why don’t we let this gentleman here, who’s got some strong feelings, summarize?’...And he said, ‘You know, we were kind of wondering in our group why none of us have said anything yet.’ And then he said, ‘We also said that we don’t like the word ‘retarded,’ and we think the Association for Retarded Citizens should change its name.’ Oooh, did that ever—they really got pissed at me then. This guy that was the head of Bevin Lodge on Vancouver Island, he said that he didn’t appreciate me stirring things up. And I said, ‘Oh, I didn’t realize that that’s called ‘stirring things up,’ getting the people involved in their own lives, and speaking for themselves. I didn’t realize that that was such a problem.’⁵⁰

When they returned to Salem, the people living in the community, as well as some people from the institution, began meeting in earnest. The core group grew and evolved into a completely self-run entity and one night everyone voted to try another convention.

⁵⁰ Dennis Heath. “Self-Advocates,” in *What We Have Done: An Oral History of the Disability Rights Movement*, ed. Fred Pelka (Amherst, Massachusetts: University of Massachusetts, 2012), 327, 328.

The group planned everything without Heath's advice and ran into the predictable problems inherent in producing such a large meeting. They decided that no helper would ever attend a People First convention. Though it took many months, the planners worked through the issues, problem solving the logistics of venue, meals, sleeping, and economics. Eventually, the first People First convention hosted about five hundred participants and was covered by the local media.

After the convention, they received inquiries from all over the United States, as well as Great Britain, New Zealand, Australia, Germany, India, China, and Russia. They published a small instruction manual for starting a self-governing group, for establishing an autonomous, self-advocacy center. People First groups now meet around the world. Individuals with intellectual impairment often ask People First members, instead of parents or other family members, to act as advocates in disputes with professionals. Self-determination is being achieved through the collective problem-solving abilities of the group, a concept affirmed by Rawls in his discussion of the benefits of social unions. According to Rawls, an individual's attributes are never as enriching as the community's experience, ideas, and support. Collaboration is the prime motivator in the formation of society and the prime benefit of affinity groups like People First.

Nancy Ward, a self-advocate with People First, when asked to describe what factors most influence her quality of life in the community, states:

Becoming a self-advocate and seeing myself as a person.
Because in seeing myself as a person that started me to start

questioning things that were going on in my life and to develop a better life for myself...⁵¹

This self-sense of ability was difficult to achieve because Ward's parents, fueled by fear of any risk, resisted her independence. Ward states

...when I became an adult, of course the natural thing to want to do was to move away from home so this is what I wanted to do, but my parents wouldn't let me move away until I was 25, and then I had to move into the system...I couldn't understand why my parents were telling me I needed to be in this kind of structured setting...⁵²

Ward worked in a sheltered workshop during the period she lived in the large group home mentioned above. Her supervisor became ill and Ward would take over her supervisory duties when doctor appointments required her absence. When the supervisor finally had to quit her job, Ward was encouraged by people within her workshop to apply for the supervisory position. She says, "...but no matter how hard people tried to do that, they couldn't convince me, because even though I was doing it, I didn't see that, because of how people in the sheltered workshop are treated."⁵³ Finally, she was convinced to apply, but upon arriving at the employment office, she was prohibited from filling out an application. To the administrators, it was inconceivable that a sheltered workshop employee could possibly become a supervisor.

⁵¹ Nancy Ward, "Reflections on My Quality of Life: Then and Now," in *Quality of Life: Perspectives and Issues*, ed. Robert A. Schalock (Washington, D.C.: American Association on Mental Retardation, 2009), 15.

⁵² Nancy Ward, "Reflections", p. 11.

⁵³ Nancy Ward, "Self-Advocates" in *What We Have Done: An Oral History of the Disability Rights Movement*, ed. Fred Pelka (Amherst, Massachusetts: University of Massachusetts, 2012), 334.

When a new supervisor was hired a few weeks later, Ward was required to train her. She says, “Well, that really pissed me off, so I quit and went and got my own job.”⁵⁴ She was hired by the social service system in Nebraska, called the Service Advisory Committee. At that time, efforts were underway to teach self-advocacy skills to the clients. Ward says, “...it’s hard to have the person you see as your boss teaching you how to advocate for yourself, because of course you’re not going to talk back. And so that’s why they thought that it would be a good idea to hire me.”⁵⁵ Ward was to teach clients how to advocate ultimately for the closure of the sheltered workshop system. She laughs, “I loved having that kind of power.”⁵⁶

In another instance of self-reporting, Connie Martinez from People First Capitol Group, states, “I’d like to say a few things about the quality of life of people like me. We can have—and now I *do* have—a good quality of life, but we still have to fight for it. We have to take back control of our lives from the KEEPERS, from the professionals.”⁵⁷ She continues:

When I was little, the doctor told my parents that I would never be able to take care of myself and that they could put me away...even to this day, my mother doesn’t believe that I have control of my life...I’ll always be ‘pobrecita Connie’ to her. She’ll always pity me and always be angry at me because she still believes the doctor even when she sees different.

⁵⁴ Nancy Ward, “Self-Advocates” in *What We Have Done*, 334.

⁵⁵ Nancy Ward, “Self-Advocates” in *What We Have Done*, 335.

⁵⁶ Nancy Ward, “Self-Advocates” in *What We Have Done*, 335.

⁵⁷ Connie Martinez, “A Dream for Myself,” in *Quality of Life: Perspectives and Issues*, ed. Robert A. Schalock (Washington, D.C.: American Association on Mental Retardation, 2009), 3.

My parents didn't put me away, and finally I'm taking back my life, after losing years of it to the wrong information. But I wonder how many people are under lock and key because that doctor thought he could play God?

My parents always had a dream for my brothers and sister for when they grew up, but nobody ever had a dream for me, so I never had a dream for myself. You can never have a good life if nobody ever has a dream for you unless you learn to have a dream for yourself. That's what I had to do, and now I have a dream for myself: a little casa, a garden with flowers and peppers and tomatoes, a loved one to share my life with—and more. Even if I don't get all those things, I know I'm alive now.⁵⁸

Many people with cognitive impairment are not supported in developing a notion of desired ends and thus are robbed of the seed, which blooms into a sense of self for typical children. All but the virtually vegetative need a dream and withholding this psychological nutrition constitutes an immoral act just as surely as withholding food and water. Dreams are not withheld by hateful people, rather by parents and educators who have absorbed the deeply held, societal belief that dreams, particularly dreams on the edge of possibility, lead to disappointment as risk leads to danger. This notion is true, but dreams and risk also lead to growth and freedom and must be instilled in each and every child so that a maximization of autonomy can occur.

Recalling an instance of initially frustrated self-determination, which, when handled appropriately, became a door to self-knowledge and freedom, Martinez says:

I went home (from school) and told my mom, 'Mom, there is going to be a high school trip to the ocean. I have never been there before and I want to go...I want to be with people, and with nature.' And my mother said, 'No, you're going to get lost. You're not going out by yourself. We'd be too concerned and worried.' ...The doorbell rang and

⁵⁸ Connie Martinez, "A Dream for Myself," 3-4.

my mother answered. It was the teacher. She had flowers and a card from the other students and a list of names of people who wanted me to be able to go on the trip. She told my mother she wanted me to come on the trip. She said she would take responsibility for me. At first, my mother said, 'No, no.' And then the teacher came back again, and she convinced my mom to let me go...My mother took me shopping to get new clothes for the trip. The day (of the trip) I got up early. I would never get up early, but I did this time. My mom fixed my lunch and she and my father took me to the school and watched me get on the bus. They called my name on the bus. I figured the teacher was going to babysit me like they always did at church and wherever else I went; but it was better than not to go to the trip. Even as they watched over this little retarded girl, I would be happy. So half of me was happy, half was not.

And then we started to get near and I saw gorgeous things I'd never seen before in my life—mountains and big trees and everything green, green, green. And the sky was so blue! I just enjoyed it all and my heart was beating fast. And we finally got there. And the door to the bus opened and the teacher said, 'Connie, the door is opened. Go enjoy yourself and be with your friends.' I thought she was going to watch over me and instead she said go out there. So I jumped into the sand and ran in the sand and just felt good. I took off my shoes. I forgot my lunch.

Did you ever see a bird in the cage? I was that bird. That teacher opened the door to the cage and I flew—it was the first time I was free...And when I came home to Sacramento I wasn't the same anymore...I had changed. There was something inside me hungry to be free.

I couldn't accept that my mom would watch over me, that they were going to watch over me, that they know best for me. I couldn't accept that any more. I tried to fight it, but it was too strong, and it got stronger and stronger. I'm not saying that my mom didn't love me, but I couldn't live the negative. I knew I had to be on my own, to fall down on my face if I had to (and I have, plenty, and yes, I've been

hurt), but I knew I would get up and start over again. And I've done that.⁵⁹

The author does acknowledge that all will at some time lack autonomy and that some will never be self-determining, but insists that such an assumption has no place at the foundation of a theory, halting, as it does, possibility in its tracks. Furthermore, education can minimize the risks inherent in dependence. David Goode, professor of sociology and anthropology at City University of New York, acknowledges the importance of risk taking in the education of people with cognitive impairment. He says, "Most educators agree that risktaking is crucial in the educational process. Special education curricula should actively and systematically address independence and integration as goals."⁶⁰

Robert Edgerton, professor emeritus of anthropology at the University of California at Los Angeles addresses the issue of risk taking as well:

When I describe the lives of some of the mentally retarded people we have studied for almost 30 years to audiences of nonretarded people, the reaction is often one of horror or revulsion and demands that I as a 'responsible scientist' take action to remove these people from their deplorable life circumstances. When I protest that I have no such right and that the people involved are quite satisfied with their lives—and themselves—the reaction is typically one of frank disbelief.

One of these mentally retarded people whose quality of life worries others is a 58 year-old man with an IQ of 54. He lives in a single room occupancy hotel in a rundown and crime-ridden part of downtown Los Angeles. He has a

⁵⁹ Connie Martinez, "A Dream for Myself," 5-6.

⁶⁰ David A. Goode, "Thinking About and Discussing Quality of Life" in *Quality of Life: Perspectives and Issues*, ed. Robert A. Schalock (Washington, D.C.: American Association on Mental Retardation, 1990), 53.

dangerous yet personally rewarding job as the night manager of a laundromat frequented by homeless people, prostitutes, and drug dealers. His sexual partners are drug-using prostitutes, one of whom recently contracted AIDS. There is no doubt that this man works very hard for the money he makes, that he is frequently in physical danger, and that his repeated exposure to AIDS could be life threatening. Yet he lives in a network of friends and acquaintances who value his friendship and help, and who do not know or care that he can neither read nor write. To many people he is loved and respected. He is as satisfied with the quality of his life as anyone I know.⁶¹

Degrees of dependence exist along a continuum, so most can achieve some level of autonomy, even if that autonomy is unconventional. Acknowledgement of this fact, rather than an immediate negation of this possibility, will allow deeper examination during which, in addition to education and its potential for autonomy generation, theory might find other avenues leading to participation, contribution, and representation. Furthermore, determinations of inability must be deferred until appropriate educational opportunities are available to all children with impairment and, even at that point, might be inappropriate. And most importantly, regardless of a person's position on the continuum of autonomy—regardless the degree or manner of his contribution—theory must assure the availability of rights. Whether those rights are claimed by an individual, a surrogate, or as a class action, the author feels most secure with a rights-based system. People with severe impairment, with their social history of mistreatment must have nothing less.

⁶¹ Robert B. Edgerton, "Quality of Life from a Longitudinal Research Perspective," in *Quality of Life: Perspectives and Issues*, ed. Robert A. Schalock (Washington, D.C.: American Association on Mental Retardation, 1990), 151.

Care theory, as well as an offering of Anita Silvers and Leslie Pickering Francis referred to as *justice through trust*, with their marginalization of rights, depend—dangerously, the author believes—on people acting kindly and responsibly in interactions with people with severe cognitive impairment. Because Silvers and Francis assume that people with severe impairment are incapable of reciprocity and therefore “outliers” within the realm of the social contract, they, in investigating ways that all might participate in contracting, imagine a unique contribution to the act of contracting itself. Rather than seeing contracting as necessarily adversarial, they focus on the benefits inherent in contracting parties operating from a position of mutual trust, rather than fear and expectations of selfishness. If a history of trust can be established, with each successful leap of faith manifesting in a positive outcome and therefore a progressive deepening of trust, enforcement of the contract will be less costly and society will become progressively better off. Trust can also act as a lubricant for future agreement and the workings of society will progress with less friction. If people with severe cognitive impairment can trust that their wellbeing will be assured, contracting can commence within that dynamic, rather than the atmosphere of bargaining, to which they cannot be a party. Silvers and Francis say:

Unlike bargaining, trusting is a human interaction that neither requires sophisticated ratiocination, nor relies on others’ material contributions, to compel constancy. Small children can sense the consequences of being inconstant, unreliable, or dishonest—that is, of being untrustworthy—well enough to be deterred by them. So can most people with reduced cognitive capacities. Trusting is essential to contracting but, unlike bargaining, is accessible to almost everyone, whether disabled or nondisabled. Even the most vulnerable individuals may be parties to trust. The trustworthiness of their social and political situations will

affect whether trusting is easy for them or is, instead, terrifyingly difficult in virtue of their vulnerability.⁶²

The author finds himself longing for a world where society would merit the trust of people with severe cognitive impairment and their allies. To require blind trust, as a condition of participation, from such a vulnerable and historically neglected and abused population, is asking for the suspension of innate human internal guidance. Instinctive caution is a basic survival tool and therefore only once the powerful have established a strong history of reliability might they be trusted, and never, the author believes, should trust be required as a precondition of participation or a sole measurement of value.

Silvers and Francis believe that their system will encourage the powerful to act honorably. They state that if a potential bargaining partner observes another person acting in a trustworthy way toward a much more vulnerable individual, that observer will be more inclined to trust in the other's faithfulness and honor when making their own agreements with him. Thus, the powerful have a strong inducement to be trustworthy in their dealings with people with severe cognitive impairment who are "unable to proffer material incentives or impose penalties."⁶³

While this idea has merit in certain circumstances, the fact that its success depends on voluntary behavior is problematic. The author's observations of some of the powerful in society lead him to believe that their opinion of an individual acting honorably in dealings with a vulnerable other might just as well describe a fool. The author, again, is further concerned that a theorist—Silvers—who herself is physically

⁶² Anita Silvers and Leslie Pickering Francis, "Justice through Trust: Disability and the 'Outlier Problem' in Social Contract Theory," *Ethics* 116 (Oct. 2005): 68-69.

⁶³ Anita Silvers and Leslie Pickering Francis, "Justice Through Trust," 69.

impaired, would be unable to see other ways in which people with severe cognitive impairment contribute to society without the need of stripping individuals and their allies of caution and often well-placed skepticism. In fact, he is entirely dismayed. Silvers and Francis continue:

...the mutual deference elicited by the dynamic of trusting and being trusted should induce contractors to deal respectfully rather than paternalistically with whoever becomes dependent, for however short or long a time. Indeed, a principle calling for the most capable to give, or give over, to the least capable and describing the circumstances thereof well might be called for to nourish a climate of trust by strengthening fairness and extending justice to everyone.⁶⁴

One problem here, as the author sees it, is that Silvers and Francis are imposing a substantive rule that the powerful alone among the contractors must observe in order for the construct to be successful. The system must be gamed to function justly. This is not a universal requirement. Rawls, on the other hand, rather than impose, expects that the principles of justice will be a likely outcome of operating under a veil of ignorance. The veil is a procedural constraint, applicable to all (including those with impairment in the author's revised model) as a moral imperative leading to a just outcome. Additionally, people with severe cognitive impairment can do nothing but be deferential, while the deference of the other is voluntary, or worse, charitable, and can be withdrawn without redress. The delivery of essential goods cannot be capricious and for this reason, the neglect of a rights-based approach is dangerous.

Even well meaning individuals, in a rights-deficient atmosphere, may pose a threat to vulnerable populations. People, even those with benign intentions, may have

⁶⁴ Anita Silvers and Leslie Pickering Francis, "Justice Through Trust," 70.

erroneous ideas about life with severe impairment and may infuse interaction with pity and patriarchal behavior rather than empowerment. This is the legacy of isolation. Even an endowed chair at Princeton University, who has directed his abundant intellect towards the elimination of cruelty to animals, poses a threat to people with severe impairment, due to profound misunderstandings.

Peter Singer *Knows I Suffer*

*I'm going to tell my kids a bedtime story
A play without a plot
Will it have a happy ending?
Maybe yeah, maybe not
I tell them life is what you make of it
So beautiful or so what—Paul Simon, *So Beautiful or So
What**

In *Practical Ethics*, Singer says of a child born with spina bifida, the author's impairment:

When the life of an infant will be so miserable as not to be worth living, from the internal perspective of the being who will lead that life, both the 'prior existence' and the 'total' version of utilitarianism suggest that, if there are no 'extrinsic' reasons for keeping the infant alive—like the feelings of the parents—it is better that the child should be helped to die without further suffering.⁶⁵

Singer's position persists, whether the impairment is physical, cognitive, or combined in nature. He justifies the use of euthanasia, as a solution to the problem of "suffering," by the fact that a newborn does not have preferences as to his or her long-term ends, and his

⁶⁵ Peter Singer, *Writings on an Ethical Life* (New York, New York: Harper Collins Publishers, 2000), 188.

or her euthanizing is non-voluntary rather than involuntary. Following this premise, he also finds acceptable the euthanizing of anyone, even an adult, whom he determines to be suffering, who is also unable to conceive of his or her own ends, and if once rational, never expressed preferences.⁶⁶

Singer's reliance on the lack of self-awareness in a newborn, as to his or her future circumstances and preferences, to morally excuse euthanasia, in conjunction with his unwillingness to see beyond his own ableist notion of the inevitable suffering of those with severe impairment, renders his argument specious. Though many adults with severe impairment have offered their personally experienced perspectives, which challenge his assumption of suffering, Singer's position continues to fail to consider the many variables within lives lived with impairment, focusing, instead, exclusively on pain. All lives contain pain, but when considered holistically are also filled with pleasure and certainly worth living. Harriet McBryde Johnson, whom Singer invited to Princeton University, as a member of the disability community, to represent opposition to his position, reveals a discussion that took place, which demonstrates Singer's thought-path in her book *Too Late to Die Young*. She asks why Singer singles out infants with impairment for death. Singer offers that both biological and adoptive parents prefer healthy babies. Johnson counters with the fact that adoptive parents also statistically fail to embrace mixed-race babies. "Wouldn't a law allowing the killing of these undervalued babies validate race prejudice?" Johnson asks. Singer agrees that that would be an unacceptable outcome.

⁶⁶ Peter Singer, *Practical Ethics*, (New York, New York: Cambridge University Press, 1993), 97-98, 182. See also Peter Singer, *Writings*, 127-128, 180-182. For a discussion of whether interests are dependent on self-awareness see F.M. Kamm, "Feminine Ethics: The Problem of Distance in Morality and Singer's Ethical Theory," in *Singer and His Critics*, ed. Dale Jamieson (Malden, Massachusetts: Blackwell Publishers, 1999), 168.

Johnson continues, “What’s the difference? Preferences based on race are unreasonable. Preferences based on ability are not. Why?” Singer’s answer speaks to a dangerous misunderstanding about people with impairment. The reason Singer singles out babies with severe impairment is that they are intrinsically “worse off.”⁶⁷ He makes pernicious assumptions here, which are patriarchal in their imposition of perspective and simply wrong. Johnson states, “...I have trouble with basing life-and-death decisions on market considerations when the market is structured by prejudice.”⁶⁸ The author would like to offer what he believes is an interpretation of Johnson’s language. Parental preference based on the difficulties a child with severe impairment might be expected to encounter cannot be seriously considered until the concept of “being a burden” ceases to exist. If infanticide is on the table, the pressure to eliminate a future “burden to society” will become a socially coercive element in that parental decision.⁶⁹

The author believes that the usefulness of a theory stems from the degree of truth in its basic assumptions and for this reason, huge pieces of Singer’s offering suffer from his unnecessarily faulty premises. Because his position threatens the disability community, the author believes it requires analysis and rebuttal, despite the position of many within the community that attention to Singer’s views risks legitimizing them. The

⁶⁷ Harriet McBryde Johnson, *Too Late to Die Young* (New York, New York: Henry Holt and Company, LLC, 2005), 207.

⁶⁸ Harriet McBryde Johnson, “Unspeakable Conversations or How I Spent One Day as a Token Cripple at Princeton University,” *New York Times Magazine*, Feb. 16, 2003, 53.

⁶⁹ Marta Russell develops this point from the perspective of an adult with impairment being asked to decide about physician-assisted suicide in Marta Russell, *Beyond Ramps: Disability at the End of the Social Contract* (Monroe, Maine: Common Courage Press, 2002).

author wishes to clarify that he in no way finds Singer's views on infanticide legitimate; in fact he finds them morally repugnant. They, unfortunately, do coincide with and encourage many, less visible, but equally disturbing perspectives about lives lived with impairment. The author fears that if Singer's "reasoned debate" fails to receive appropriate criticism, the many books, lectures, and articles offered by this popular intellectual will solidify an already generally unspoken public mindset, which has catastrophic social and political consequences.⁷⁰

Singer states, "...My views in no way threaten anyone who is, or ever has been, even minimally aware of the fact that he or she has a possible future life that could be threatened."⁷¹ Singer definitively states on many occasions that it is a kindness to assist with the death of severely impaired babies because they cannot have meaningful existences. This position encourages society in the belief that people are justified in determining the quality of life for another as well as judging the potential of that life. Unfortunately, policy, both social and medical, moves in an increasingly utilitarian direction and the fact that Singer is involved in practical applications of his philosophical positions, unquestionably makes his arguments dangerous. Furthermore, despite the fact that utilitarian arguments are based in quality of life issues, the author questions whether the driving force behind utilitarian decisions is truly concern for the quality of life experienced by the person with impairment and not a concern for the quality of life,

⁷⁰ See Joshua Lederberg, "A Geneticist Looks at Contraception and Abortion," *Annals of Internal Medicine* 67, no. 3 (Sep. 1967): 25-27.

⁷¹ Peter Singer, *Practical Ethics*, 357-358.

defined by the weight of the wallet, of the unimpaired members of society. The author is in agreement with Rawls when he says:

Each person possesses an inviolability founded on justice that even the welfare of society as a whole cannot override. For this reason, justice denies that the loss of freedom for some is made right by a greater good shared by others. It does not allow that the sacrifices imposed on a few are outweighed by the larger sum of advantages enjoyed by many.⁷²

Singer condemns various German academic institutions, disability rights groups, and political activists who have sought to bar him from discussing euthanasia on German soil. He is, at once, appalled both by what he considers a violation of his freedom of speech and by what he refers to as a misconstruction of his ideas. He says:

...it is easy to imagine that the shadow of Nazism prevents any rational discussion of anything that relates to euthanasia. It avails little to point out that what the Nazis call 'euthanasia' had nothing to do with compassion or concern for those who were killed but was simply the murder of people considered unworthy of living from the racist viewpoint of the German *Volk*.⁷³

In fact, in Nazi Germany, arguments surrounding the killing of people with impairment were entwined with the idea of "mercy killings" in much the same way Singer constructs his proposals. Like Singer's arguments, German eugenics justifications are peppered with quality of life references. In the first case of euthanasia of a baby with impairment, in 1938, Gerhard Herbert Kretschmar's father sought help from the Führer in authorizing a "mercy killing" of his infant. Hitler ordered his personal physician, Karl

⁷² John Rawls, *A Theory of Justice*, 3.

⁷³ Peter Singer, *Writings*, 316.

Brandt, to verify the veracity of the father's description of his child as blind, with missing limbs, and with mental deficiencies, and if accurate to compel the physicians at the University of Leipzig Hospital to euthanize the baby under Hitler's orders.⁷⁴ This behavior continued under the supervision of the Reich Commission for the Scientific Registration of Hereditary and Constitutional Severe Disorders. Registered children, reported by their doctors, were moved to "children's divisions" where "they were killed either by barbiturate poisoning—Luminal or Phenobarbital was mixed into their food—or by starvation. In both cases, it took many days for each child to die."⁷⁵ Prosecution of complicit doctors was implicitly forbidden by Hitler and their immunity was guaranteed by Brandt on Hitler's orders.⁷⁶ By the fall of 1939, the program was formally recognized and named T-4 after the address of the Patient Transport Corporation, the conduit through which the euthanasia and eventually Final Solution programs emanated. By this time, adults with physical and intellectual impairment as well as those with mental illness joined children as targets for elimination. In 1939, there were an estimated 300,000 "undesirables" housed in holding psychiatric hospitals and clinics. By the end of World War II, less than 40,000 remained.⁷⁷ The annihilation of people with impairment was alternately termed "help for the dying," "destruction of life devoid of value," "killing the

⁷⁴ Marta Russell, *Beyond Ramps*, 25.

⁷⁵ Stephan L. Chorover, *From Genesis to Genocide, The Meaning of Human Nature and the Power of Behavior Control* (Cambridge, Massachusetts: The MIT Press, 1980), 102.

⁷⁶ Robert Jay Lifton, *The Nazi Doctors: Medical Killing and the Psychology of Genocide* (New York, New York: Basic Books, 2000), 51.

⁷⁷ Stephan L. Chorover, *From Genesis to Genocide*, 101.

incurable,” and the more forthright abomination—“destruction of useless eaters.”⁷⁸ Thus, a failure to draw distinct delineations between Singer’s “compassionate” euthanasia and the programmatic removal of the burdensome as a social good is completely rational in the author’s view.

Singer does not draw a line at eliminating an individual’s suffering. He widens his concern for quality of life to encompass parents and family. Decisions about life and death are not the sole prerogative of the individual, whose life is in question. Parents make decisions of life and death for their child in cases where the child is unable to state a preference as to her continued existence. But on issues of life and death, which hinge on organ transplants or expensive procedures, decisions are made by boards of doctors and ethicists using criteria established by strangers, not by the individual patient or her parents, and Singer approves of this as well. How far removed is that from German doctors making determinations as to who will live and who will die, who is deserving of life and who is not?

While the Nazi regime took judgment of human worth to singularly horrendous conclusions, they were not the initiators. The long history of eugenic practices began with British scholars, Sir Francis Galton (Charles Darwin’s cousin), and separately, Herbert Spencer (originator of the term *survival of the fittest*) who, in the late nineteenth century, took the work of Charles Darwin, and transformed the idea of natural selection into a project for the “improvement” of the human race. Galton, along with colleagues in the United States such as psychologists Alfred Binet and Lewis Terman, began the use of intelligence testing to measure individual “fitness” and to create laws enforcing both

⁷⁸ Stephan L. Chorover, *From Genesis to Genocide*, 101.

sterilization and immigration restriction. By 1907, Indiana led the way by introducing a mandatory sterilization law which was upheld by the Supreme Court in *Buck v. Bell*. In his majority opinion, Justice Oliver Wendell Holmes stated:

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world if, instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind...Three generations of imbeciles are enough.⁷⁹

Eventually thirty-three American states passed mandatory sterilization laws. By the 1920s, it is little wonder German eugenicists looked to their colleagues in the United States for inspiration and called American law one of the most advanced in the area of eugenics.⁸⁰ The publication of *Die Freigabe der Vernichtung Lebensunwerten Lebens* (The Release and Destruction of Lives Devoid of Value) in 1920 by law professor Karl Binding and Dr. Alfred Hoche began the transformation of the use of eugenics in sterilization and its connection to intelligence testing into a movement of “compassionate” killing.⁸¹ Peter Singer, who the author quotes in this work as stating that people with reasoning ability are worth more than those without the ability to reason—that unimpaired people are more worthy of medical treatment than those with

⁷⁹ *Buck v. Bell*, 274 U.S. 200 (1927).

⁸⁰ Alan Gilbert, *Democratic Individuality*, (Cambridge, United Kingdom: Cambridge University Press, 1990), 409-410. For a thorough discussion on the issue of American eugenics policy and its influence on German doctrine, see Stephan L. Chorover, *From Genesis to Genocide*, 32-55.

⁸¹ Alan Gilbert, *Democratic Individuality*, 461.

impairment—that a child born with Down Syndrome is a critical disappointment to her parents, and that society should assume suffering in cases where there may be none—is either unaware of this history or self-servingly naive in failing to understand why his ideas are anathema to modern Germans.

In his *Writings on an Ethical Life*, Singer offers “simple claims” that ground his theory. Among these are:

Pain is bad, and similar amounts of pain are equally bad, no matter whose pain it might be. By ‘pain’ here I would include suffering and distress of all kinds. This does not mean that pain is the only thing that is bad, or that inflicting pain is always wrong. Sometimes it may be necessary to inflict pain and suffering on oneself or others. We do this to ourselves when we go to the dentist, and we do it to others when we reprimand a child or jail a criminal. But this is justified because it will lead to less suffering in the long run; the pain is still in itself a bad thing. Conversely, pleasure and happiness are good, no matter whose pleasure or happiness they might be, although doing things in order to gain pleasure or happiness may be wrong, for example, if doing so harms others.⁸²

Since determination of the degree of suffering and anticipated suffering, for assessing the appropriateness of infanticide, must take place before a child acquires a *desire* to live, Singer does not address any emotional suffering felt by a newborn over the idea of being held unworthy of life. While a baby, unaware of herself and her circumstances, may not anguish over Singer’s position, emotional suffering is precisely what Singer inflicts on the disability community and its allies with his intellectual contemplations. If he would open himself to the experiences of others, he would find that factors like respect, appreciation, and inclusion effectively modulate the difficulties

⁸² Peter Singer, *Writings*, xv.

inherent in physical or cognitive impairment. A variety of modalities can mitigate physical pain, but the pain born of social exclusion, ossified misunderstandings, and the treatment they engender, as well as the withholding of respect (as in ignoring input from the disability community) are harder to overcome.

Research into factors influencing self-perceived quality of life in groups of people with intellectual impairment finds that those whose locus of control is external report the lowest quality of life while others, who feel empowered by self-determination and the self-respect it engenders, describe their lives as having higher quality.⁸³ Singer's refusal to replace his own perceptions with the authentic perceptions of those who live with impairment is deeply disrespectful and disempowering. Those among the readers who have experienced patronizing comments about how they do not *really* feel the way they *think* they feel, and instead feel in another suggested way, know how this behavior seeks to dominate and demean. The author wonders what Singer achieves by insinuating his opinions in an arena where he has absolutely no experience, while denying the validity of authentic experiences.

⁸³ According to Robert Schalock, et al, quality of life is affected by "the degree of independence, productivity, and community integration that a person experiences." When Schalock, et al interviewed "persons in programs that more nearly approximated normal community life and that imposed fewer environmental restrictions" they observed a marked rise in quality of life scores. Individuals working and living in normalized settings have greater access to experiences and activities that quality of life indices would tap...The presence or absence of environmental restrictions are also indicators of the amount of control a person experiences in his or her daily life." (Michael L. Wehmeyer, "Employment Status and Perceptions of Control of Adults with Cognitive and Developmental Disabilities," *Research in Developmental Disabilities* 15, no. 2 (1994): 120. See also Michael L. Wehmeyer and Michelle Schwartz, "The Relationship Between Self-Determination and Quality of Life for Adults with Mental Retardation," *Education and Training in Mental Retardation and Developmental Disabilities* 33, no. 1 (1998): 3-12. See also Michael L. Wehmeyer, "Employment Status and Perceptions of Control of Adults with Cognitive and Developmental Disabilities," *Research in Developmental Disabilities* 15 no. 2 (1994): 124.

Singer states, "...pain is still, in itself...a bad thing."⁸⁴ How can he imagine that the misconceptions he encourages and the damage he inflicts by questioning whether people with severe impairment are worthy of life and, in the case of severe cognitive impairment, worthy of personhood, are not pain generating? When a new parent greets with anguish the birth of a baby with impairment, does it occur to him that the position he and other theorists posit with cold and rational civility are, at least in part, at fault? Does Singer fail to see that what matters in the determination of whether a new baby is a person is not whether it has potential for reasoning, but rather that parents *experience* their new baby as one of their own, a member of their family. This intuitive response must find acceptance and precedence over any coldly rational criteria, which determines the child's status, if one holds that the infliction of pain is bad.⁸⁵ The emotional pain Singer and others inflict in the name of academic argument is far more egregious than the physical pain people with impairment suffer. Physical pain generally can be mitigated, while the denial of self-authorship and the pain that it generates is without a pharmaceutical, naturopathic, or surgical remedy. Yet, Singer is not alone in his destructive ideology.

Until he began research for this work, the author had no idea that his impairment caused "hopeless suffering with no means of alleviation."⁸⁶ According to Eduard

⁸⁴ Peter Singer, *Writings*, xv.

⁸⁵ See Susan L. Krantz, *Refuting Peter Singer's Ethical Theory: The Importance of Human Dignity*, (Westport, Connecticut: Praeger Publishers, 2002), 84-85 for a discussion of intuitive experience and 103 for a discussion identification with close relations regardless of intellectual capacity.

⁸⁶ Eduard Verhagen, J.J. Sol, O.F. Brouwer, and Pieter Sauer, "Deliberate Termination in Life of Newborns in the Netherlands; Review of All 22 Reported Cases between 1997 and 2004," *Ned Tijdschr Geneeskd* 149, no. 4 (January 22, 2005): 183, 186.

Verhagen, co-author of the Groningen Protocol, the Dutch national guidelines, which outline circumstances meriting euthanasia of infants, between the years 1997 and 2004, twenty-two cases of “deliberate termination of life,” took place in the Netherlands. All cases involved babies with spina bifida with hydrocephalus.⁸⁷ Verhagen and his co-author of the Groningen Protocol, Pieter Sauer, divide newborns and infants for whom they consider the discussion of euthanasia appropriate into three categories. The first group includes infants with no chance of survival. The second, infants considered to have a very poor prognosis who are also dependent on intensive care services. The third, and most stunning to the author, involves infants deemed to be suffering unbearably with a hopeless prognosis, but who are not dependent on intensive medical treatment, such as those with severe spina bifida who, according to these utilitarians, will have a “very poor quality of life even after many operations.”⁸⁸ Singer states:

Many doctors and theologians, including those who are quite conservative in their moral thinking, agree that when a patient's prospects of a minimally decent quality of life are very poor, and there is no likelihood of improvement, we are not obliged to do everything we could to prolong life.⁸⁹

The author wonders who should make the determination about whether a life contains potential quality.

⁸⁷ Eduard Verhagen, J.J. Sol, O.F. Brouwer, and Pieter Sauer, “Deliberate Termination,” 183.

⁸⁸ Eduard Verhagen and Pieter Sauer, “The Groningen Protocol—Euthanasia in Severely Ill Newborns,” *The New England Journal of Medicine* 352, no. 10 (March 10, 2005): 959.

⁸⁹ Peter Singer, *Writings*, xvii.

Singer comments:

...parents of severely disabled newborn infants should be able to decide, together with their physician, whether their infant should live or die. If the parents and their medical advisor are in agreement that the infant's life will be so miserable or so devoid of minimal satisfactions that it would be inhumane or futile to prolong life, then they should be allowed to ensure that death comes about speedily and without suffering. Such a decision might reasonably be reached, if, for instance, an infant was born with anencephaly (the term means 'no brain' and infants with this condition have no prospect of ever gaining consciousness); or with a major chromosomal disorder such as trisomy 18, in which there are abnormalities of the nervous system, internal organs, and external features, and death always occurs within a few months, or at most two years; or in very severe forms of spina bifida, where an exposed spinal cord leads to paralysis from the waist down, incontinence of bladder and bowel, a buildup of fluid on the brain and, often, mental retardation.⁹⁰

To solidify his point, he continues:

Spina bifida means, literally, a 'divided spine'. In serious cases, the baby is born with a part of its spine split and the spinal cord exposed. The nerves which run along the spine will then be damaged. The result is partial or complete paralysis of the legs, and no ability to control the bowel or bladder. The spine may also be deformed. Intellectual disability is often present in people seriously affected by spina bifida...Until the 1950s, almost all babies born with spina bifida died soon after birth. Sometimes this was because midwives and family doctors made sure that they did not live; but even if the doctors did their best, the open wound over the spine was sure to become infected, and in the days before antibiotics, this was likely to prove fatal. Operating on the baby to close the wound on the spine only meant that the cerebro-spinal fluid which would have leaked out of the wound now built up in the brain, where it caused the baby's head to swell, and often led to brain damage.

⁹⁰ Peter Singer, *Writings*, 307.

In the 1950s, however, antibiotics became available, and a way was found to drain the cerebro-spinal fluid into the bloodstream. Suddenly it was possible to save the lives of thousands of children who would otherwise have died.⁹¹

Singer refers to a reversal in opinion by a physician, John Lorber, who pioneered this new approach to the treatment of spina bifida. Lorber expected babies to have drastic improvement in health outcomes if they received treatment to close the myelomeningocele (the cyst containing neural material that forms outside the body due to a failure of the spine to close over the spinal cord) and underwent shunting.

Lorber was at first enthusiastic about the new mode of treating these babies with spina bifida. In 1963, together with two colleagues, he published an influential paper stating that every infant with spina bifida must be operated on as soon as possible since otherwise further nerve damage could occur. In Sheffield and in many other centres in Britain and America this was the way spina bifida was handled for the next few years. The parents were rarely consulted about this decision—they were simply told that their baby needed an operation, and given a form to sign. But the operation to close the wound on the back of the spine was only the beginning of the treatment. After that a tube with a one-way valve was installed to drain the excess cerebro-spinal fluid from the head into the bloodstream. Then orthopaedic operations were needed to correct deformities of the spine and hip. Some children needed thirty or forty orthopaedic operations before they had finished school.⁹²

After a decade of universal active treatment of all babies with spina bifida, Lorber began to have doubts about what he and his colleagues were doing. He analysed the records of the 848 children they had treated in Sheffield. Half had died, most of these during the first year of life. Of those

⁹¹ Peter Singer, *Rethinking Life and Death: The Collapse of our Traditional Ethics* (New York, New York: St. Martin's Griffin, 1994), 115-116.

⁹² Peter Singer, *Rethinking*, 116.

who had survived, only six had no handicap, and seventy-three were only moderately handicapped. More than 80 percent were severely handicapped: that is, they had at least two, but usually more, of the following conditions: no bowel and bladder control, or a urinary bypass with frequent kidney infections and progressive chronic kidney damage which sometimes led to kidney failure; paralysis to such a degree that they were unable to walk without caliper splints, crutches, or other appliances and had to rely on a wheelchair for part of the day; pressure sores on feet, knees, or buttocks; hydrocephalus which was treated by a drainage tube, requiring new operations to deal with frequent complications. In addition to these physical problems, approximately one-third of the surviving children were intellectually disabled.

In the light of these figures, Lorber decided that the initial enthusiasm for the new mode of treatment had led to its being used without sufficient reflection. He called for a reassessment of priorities 'to insure that, with all the intensive effort and good will, we shall not do more harm than good'.⁹³

Singer in the paragraph above, from *Rethinking Life and Death*, published in 1994 is recounting Lorber's reconsideration, which took place in 1972. He neglects to update the improved outcomes experienced by aggressive and improved treatment over the intervening twenty-two years. Why does Singer present outdated information? Surely, he has access to modern outcomes.⁹⁴ This is not to be considered merely a failure of scholarship, but a moral failure, as well. Moral philosophers, like Singer, by the nature of their work, are to be held responsible for the political and social consequences of their ideas.

⁹³ Peter Singer, *Rethinking*, 117.

⁹⁴ For another incident of biased cherry picking on the part of Singer, see Stephen Drake, "Not Dead Yet!" in *Peter Singer Under Fire: The Moral Iconoclast Faces His Critics*, ed. Jeffrey A. Schaler (Peru, Illinois: Carus Publishing Company, 2009), 216, 217.

The author does not suggest that his experience is universal, but he would like to point out that he has never experienced kidney problems, pressure sores, or spinal or hip alignment surgeries. He controls his bowel and bladder functions with medications and although he has undergone eighteen surgeries to date, uses a wheelchair, and requires the support of a personal care assistant, he has never been clinically depressed, has successfully completed his formal education with this work, and has fulfilling relationships with friends and family.

The author anxiously awaits requests for his opinion on quality of life with spina bifida. He has many friends with a variety of impairments, who enthusiastically anticipate quality of life questions along with him. If the reader questions the appropriateness of comments about physical impairment in a work that seeks to investigate personhood and citizenship for people with severe cognitive impairment, the author finds commonality among all experiences of disability. All experiences are misconceived and all individuals with impairment experience reduced expectations.

When people with cognitive impairment reflect on factors that influence their quality of life, not surprisingly, they see it as “composed of those same factors...that are important to those without disabilities.”⁹⁵ People without impairment, however, lack the experience to determine how people with impairment experience these factors and relationships. “An individual with mental retardation need not have the cognitive capacity to appreciate ‘meaning’ in order to have a life of satisfying quality. This sense

⁹⁵ Allan Colver, et.al., “Study Protocol: SPARCLE—A Multi-Centre European Study of the Relationship of Environment to Participation and Quality of Life in Children with Cerebral Palsy,” *BioMed Central Public Health* 6 no. 105 (2006): 5.

of satisfaction is understood best from the individual's point of view."⁹⁶ No human being can authentically determine the experience of another, and certainly not to the degree necessary to make life-ending decisions. The author finds it strange that scientists rarely analyze quality of life in the case of people without impairment or other health concerns, though surely factors outside of health and intellectual status affect one's quality of life. Well-positioned people have their hearts broken, lose things they value, and feel misunderstood. Others may be undereducated and have economic challenges; they may have experienced poor parenting or bigotry. They may have addictions. To solely focus on impairment seems blatantly prejudiced.

Singer is the founder of The Center for Human Bioethics at Monash University in Melbourne, Australia. One of its primary missions is the education of health care professionals in making decisions dealing with bioethical dilemmas. The reader can be certain that the professionals there are learning how to determine the quality of life of people based on a very limited view of what constitutes a life and without considering valid perspectives.⁹⁷

The author rejects one such methodology for determining quality of life, which is nakedly cold-blooded in its formulaic nature and used practically within the medical ethics community, notably in Europe and Australia, to assist with life and death considerations. If the author ultimately requires a donated liver to save his life from the

⁹⁶ David L. Coulter, "Home is the Place: Quality of Life for Young Children with Developmental Disabilities," in *Quality of Life: Perspectives and Issues*, ed. Robert A. Schalock (Washington, D.C.: American Association on Mental Retardation, 1990), 61.

⁹⁷ For examples of medical ethics positions held by professors at Monash University see "After birth abortion: why should the baby live?" by Alberao Giubilini with Francesca Minerva and "Critical Notice: Why Killing is Not Always Worse—and is Sometimes Better—Than Letting Die" by Helga Kuhse.

consequences of a lengthy association with hepatitis C, under this system, the quality of his remaining life might be judged against that of others waiting to receive the same organ. A medical ethics team might assess his life in terms of *Quality Adjusted Life Years* (QALYs).⁹⁸ As someone with impairment, each of his remaining years, using QALYs, adjusts to some portion of a year. If the committee expects that he will live for thirty more years, his QALYs, unlike his able-bodied competitors, will be, perhaps, fifteen. For the defender of QALYs, those with a lower tally are less deserving of goods than others with a higher number. From the perspective of someone with impairment, the hubris involved in scientifically certifying that one year of the author's life is worth less than that of a non-impaired person's is misguided at best, and immoral, destructive, and simply evil at worst. Singer is a proponent of the use of QALYs as evidenced in his article "Why We Must Ration Healthcare."⁹⁹

The methodology used in formulating QALYs aggrieves the author. Several approaches may be used, but all involve the indifferent application of formulae based on the preferences of research subjects. These subjects include a preponderance of people who have never experienced impairment:

...researchers seek to find the point at which subjects are indifferent between two options. Under one option, subjects have a normal life expectancy, but in a reduced health state—for example, paraplegia. Under the second option, subjects have a probability p of normal life expectancy at normal health and a probability $(1-p)$ of instant death. Researchers vary p until subjects are

⁹⁸ Mark S. Stein, "Utilitarianism and the Disabled: Distribution of Life," *Social Theory and Practice* 27, no. 4 (October, 2001): 567. (The practice of using QALYs is predominately European and is not used in the United States).

⁹⁹ Peter Singer, "Why We Must Ration Health Care," *New York Times Magazine*, July 15, 2009, 42, 43.

indifferent between the two options. When a subject is indifferent between the two options, p represents the utility that he has assigned to the reduced health state. Suppose, for example, that a subject is indifferent between (1) normal life expectancy as a paraplegic and (2) a probability .75 of normal life expectancy at full health and a probability .25 of instant death. He would then have assigned the paraplegic health state a utility of .75....After subjects select utilities for states of reduced health, researchers average those individual utilities to reach a social utility. The social utility of a state of reduced health represents the reduced value of life in that state. Therefore, if the value of one year of life at full health is 1.0 and the utility of paraplegia is .75, the value of one year of life as a paraplegic is nine months of a typical life. The value of two years of life as a paraplegic is 1.5 years and so on. The value of a year of life at reduced health has been adjusted downward to reflect a lower quality of life—hence the term ‘Quality-Adjusted Life Year’ or QALY.¹⁰⁰

These research results will influence the chances of a person with impairment receiving a scarce organ or expensive procedure. The subjects who contributed their opinions about lives lived with impairment, people who base their beliefs on myths and fictions instead of actual experience, affect decisions of life and death for people like the author.

When Johnson describes common reactions on the street to her impairment as “decidedly negative” she describes the viewpoints that might inform the opinions of people who participate in setting the value of Johnson’s and the author’s lives. She describes the comments that she has encountered, including, “I admire you for being out;

¹⁰⁰ Mark S. Stein, “Utilitarianism and the Disabled,” 567. The author invites the reader to participate in a determination of their own QALY status by visiting the EQ-5D Index Score Calculator at the Oregon Health and Science University website, currently found at <http://www.ohsu.edu/epc/mdm/calculator.htm>.

most people would give up.” “God bless you! I’ll pray for you.” “You don’t let the pain hold you back, do you?” and, “If I had to live like you, I think I’d kill myself.”¹⁰¹

The author submits that he has experienced very similar comments. While visiting the Santuario de Chimayo, the Lourdes of New Mexico, a well meaning, but not sought out, resident priest assured him that he would pray for the author’s recovery from his pitiable affliction. When he discussed the long and difficult course of chemotherapy treatment needed to eradicate his hepatitis C infection with his doctor, the hepatologist was shocked that he would choose to prolong a life of misery and suffering with additional painful treatment. The prospect that a committee may evaluate the author for treatment based on melodramatic stereotypes terrifies and angers.

Even without the use of QALYs, transplant committees take a prospective patient’s impairment status into account when evaluating their qualification for an organ. In January, 2012, the Children’s Hospital of Philadelphia, met with Amelia Rivera’s parents about her need for a donor kidney to save her life. According to her mother, Chrissy Rivera, Amelia, a three-year-old with Wolf-Hirschhorn Syndrome, was turned down for transplantation because she is “mentally retarded.” When the doctor entered the conference room where Amelia’s parents waited, he placed two sheets of paper on the table. Rivera describes her reaction to the papers:

I can’t take my eyes off the paper. I’m afraid to look over at Joe (Amelia’s father) because I suddenly know where the conversation is headed. In the middle of both papers he (the doctor) highlighted in pink two phrases. Paper number one has the words, ‘Mentally Retarded’ in cotton candy pink right under Hepatitis C. Paper number two has the phrase, ‘Brain Damage’ in the same pink right under HIV. I

¹⁰¹ Harriet McBryde Johnson, *Too Late*, 2.

remind myself to focus and look back at the doctor. I am still smiling.

He says about three more sentences when something sparks in my brain. First it is hazy, foggy, like I am swimming under water. I actually shake my head a little to clear it. And then my brain focuses on what he just said.

I put my hand up. ‘Stop talking for a minute. Did you just say that Amelia shouldn’t have the transplant done because she is mentally retarded? I am confused. Did you really just say that?’

The tears. Oh, the damn tears. Where did they come from? Niagara Falls. All at once. There was no warning. I couldn’t stop them. There were no tissues in the conference room so I used my sleeve and my hands and I keep wiping telling myself to stop it.

I point to the paper and he lets me rant a minute. I can’t stop pointing to the paper. ‘This phrase. This word. This is why she can’t have the transplant done.’

‘Yes.’¹⁰²

Rivera says that, during the conference, the doctor would not even consider a kidney donation from a family member, citing Amelia’s “quality of life”, or lack thereof.¹⁰³

Pediatric Transplantation, in 2009, published the results of a study on the use of information about developmental delay in determining qualification for a solid organ

¹⁰² Chrissy Rivera, “Brick Walls,” *The Real Story About Wolf-Hirschhorn Syndrome* (blog), January 12, 2012, [http://www.wolfhirschhorn.org/2012/01/amelia/brick walls/](http://www.wolfhirschhorn.org/2012/01/amelia/brick%20walls/)

¹⁰³ Chrissy Rivera, “Brick Walls,” *The Real Story About Wolf-Hirschhorn Syndrome* (blog), January 12, 2012, [http://www.wolfhirschhorn.org/2012/01/amelia/brick walls/](http://www.wolfhirschhorn.org/2012/01/amelia/brick%20walls/)

transplant in children. 43 percent of programs “always” or “usually” consider intellectual impairment when making transplant decisions.¹⁰⁴

Entirely different ways of measuring quality of life come from arenas familiar with impairment.

It would be fair to say that Americans (with or without mental retardation) are concerned in rating the quality of their own lives with relationships, work, general material standard of living, opportunities for learning, the neighborhoods/communities/homes in which they live, health and safety, recreation/social activities, and perception of self.¹⁰⁵

The author finds greater merit in these areas of measurement than in the simplistic and inadequate methodology employed in determining QALYs or using single issue criteria.

Amazingly, a rationing protocol developed in New York in 2007 and adopted in 2009 by hundreds of hospitals across the nation, including the Veterans Health Administration facilities, proposed the withholding of scarce ventilators from H1N1 patients with serious chronic conditions including “severe, irreversible neurological conditions that are likely to be deadly.”¹⁰⁶ This would include veterans with traumatic brain injuries or spinal cord injuries, as well as individuals with neurological impairment like spinal muscular atrophy and severe cerebral palsy. The author wonders if people,

¹⁰⁴ Christopher T. Richards, LaVera M. Crawley, and David Magnus, “Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: Inconsistencies in standards across major pediatric transplant centers,” *Pediatric Transplantation* 13 (2009): 846.

¹⁰⁵ Kenneth D. Keith, “Quality of Life: Issues in Community Integration,” in *Quality of Life: Perspectives and Issues* ed. Robert A. Schalock (Washington, D.C.: American Association on Mental Retardation, 1990), 94.

¹⁰⁶ Sheri Fink, “Flu Nightmare: In Severe Pandemic, Officials Ponder Disconnecting Ventilators From Some Patients,” *ProPublica*, Sep. 23, 2009, <http://www.propublica.org/article/flu-nightmare-officials-ponder-disconnecting-ventilators-from-some-pat-923>.

already using ventilators for impairments that affect their ability to breathe independently, would be divested of their mechanical support if they were hospitalized at the time of a critical respiratory epidemic. While the law prohibits the removal of life support at the discretion of medical authorities, the pervasive attitude, that people with severe impairment live inferior lives, leads the author to question. For those who would label his concern “paranoia,” he offers the results of a survey reported in the *New England Journal of Medicine*.¹⁰⁷ A 1996 mail survey, sent to 1600 ICU nurses who subscribed to *Nursing Magazine*, with responses from 852 full time nurses, revealed that “one out of five have hastened the death of critically ill patients at least once in their careers, occasionally *without explicit permission* (author’s italics) from patients, doctors, or family.”¹⁰⁸

As further evidence for concern, Willard Gaylin, a Harvard psychologist/medical ethicist and a founder of the Hastings Center, in the October 1993 edition of *Harper’s Magazine*, states:

It is often difficult for laypeople to appreciate that good medicine does not reduce the percentage of people with illnesses in our population (what is called the morbidity rate); it *increases* that percentage. There are more people wandering around with arteriosclerotic heart disease, essential hypertension, and other expensive chronic diseases than there are in Iraq, Nigeria, or Colombia. Good medicine keeps *sick* people alive thereby increasing the number of sick people in the population; patients who are

¹⁰⁷ For a satirical look at governmental manipulation of self-worth in the disability community in times of medical rationing see Mike Ervin, “Venting Time,” *New Mobility: Life on Wheels* 19, no. 179 (August 2008): 42.

¹⁰⁸ Referring to a survey conducted by David Asch of the University of Pennsylvania and reported in the May 23, 1996 edition of the *New England Journal of Medicine*. David A. Asch, “The Role of Critical Care Nurses in Euthanasia and Assisted Suicide,” *New England Journal of Medicine* 334, no. 21 (May 23, 1996): 1374.

killed by their diseases are no longer part of the population. Even outright cures of diseases ultimately add to medical costs. We no longer talk about diphtheria rates or whooping cough rates, even though those were the two leading causes of death in children for many generations. Those diseases have ceased to exist. But they were rarely expensive. The child either lived or died, and, for the most part, did so quickly and cheaply.¹⁰⁹

Even if one accepts the basic premise that rationing is necessary and desirable due to the high cost of medical intervention, no one can successfully argue that people with severe cognitive impairment alone, experience health or pain problems that either affect their quality of life or impose the expenditure of medical dollars on society. Nonetheless, if the impairment affects rationality, Singer and other utilitarians believe that the “value” of that individual is measurably less than his rational neighbor. Singer states,

It is not arbitrary to hold that the life of a self-aware being, capable of abstract thought, of planning for the future, of complex acts of communication, and so on, is more valuable than the life of a being without these capacities.¹¹⁰

Medical ethicists and wrong-thinking medical personnel generally fail to consider any other criteria of intrinsic “value.” Singer does take into account the value individuals with severe cognitive impairment have for their families, but this does not transfer into the calculations of value used in medical rationing and he does not contemplate infanticide in cases of unimpaired, yet unwanted, children. Impairment, low health status, and/or lack of reasoning capacity are Singer’s requirements when justifying the termination of a life.

¹⁰⁹ Willard Gaylin, “Faulty Diagnosis: Why Clinton’s Health-Care Plan Won’t Cure What Ails Us,” *Harper’s Magazine*, October 1993: 59-60.

¹¹⁰ Peter Singer, *Writings*, 45.

Consider the only other circumstance wherein society takes the life of an individual—capital punishment. The death penalty is meted out for extreme crimes against society—usually murder, often a relational act—a morally reprehensible act. Society demands that its members behave in civilized ways toward each other, honoring the irreplaceable value a human life holds, at least the value it holds for the possessor of that life. In the ultimate punishment, however, society takes the life of a person who still desires to continue living when that person has committed extreme relational crimes. Yet, in reviewing medical rationing criteria, the quality of one’s relational capacities is not even mildly considered. The author sees inconsistencies here.

Singer’s second “simple claim” is:

Humans are not the only beings capable of feeling pain or of suffering. Most nonhuman animals—certainly all the mammals and birds that we habitually eat, like cows, pigs, sheep, and chickens—can feel pain. Many of them can also experience other forms of suffering, for instance, the distress that a mother feels when separated from her child, or the boredom that comes from being locked up in a cage with nothing to do all day except eat and sleep. Of course, the nature of the beings will affect how much pain they suffer in any given situation.¹¹¹

If Singer is willing to acknowledge that suffering can occur without the infliction of physical pain, must he not accept responsibility for increasing the sum of experienced misery in the world as much as the farmer who removes the calf from its mother in order to gather her milk? What of the human mother who is in despair over her newborn’s perceived inability to have a quality life, perceived lack of value, and probable lack of social acceptance due to her exposure to the perverse assumptions of Singer and others?

¹¹¹ Peter Singer, *Writings*, xv.

The author does not suggest that his inability to cook a gourmet dinner does not diminish his life in some small and infrequent way. He does not suggest that abilities driven by intellect are not life enhancing, even the “chief glory of man.”¹¹² What he does insist upon is that components of an individual’s life, which contribute to that individual’s happiness and pleasure, are so many and varied, so individual in their hierarchical standing, that Singer’s severely focused criteria fail utterly to encompass that which is pleasure and happiness generating. They might define what is pleasure and happiness generating for him...but not on any generalizable level.

Many disability rights activists have, for years, targeted Jerry Lewis’s Labor Day Telethon for protest actions. Some are astonished that people with neuromuscular disorders, living themselves with the “ravages” of these diseases, would demonstrate such anger at the Telethon. The problem is pity. Pity is not something you feel for an equal. Instead it is a response to helplessness in another. To use pity to raise money for the Muscular Dystrophy Association is to condone paternalism, ableism, and the misconception of suffering. In a response to the Telethon protesters, on the May 20, 2001 edition of CBS Sunday Morning, Jerry Lewis stated, “Pity? You don’t want to be pitied because you’re a cripple in a wheelchair? Stay in your house!” No mouthy adults with impairment, who might have important points of view about whether they find pity helpful, are held within the loving embrace of the savior of “Jerry’s Kids”! Issues of pity, and pity must be behind the “compassionate killings” endorsed by Singer, leave no room for the public’s acceptance of people with impairment as happy, fulfilled, or valuable.

¹¹² Bertrand Russell, *Principles of Social Reconstruction*, 115.

Another “simple claim” grounding Singer’s theory is:

When we consider how serious it is to take a life, we should look, not at the race, sex, or species to which that being belongs, but at the characteristics of the individual being killed, for example, its own desires about continuing to live, or the kind of life it is capable of leading.¹¹³

Having read Singer’s *Animal Liberation*, the author agrees that the cruel and heartless use of animals for food, medical experimentation, and other forms of human profit requires a strong and unacceptable commitment to compartmentalization and rationalization—one that the author has used on many occasions. Humans demonstrate such arrogance in subjugating the natural process of procreation and life to animal husbandry. The raising of lab rabbits for their use and eventual destruction in the unnecessary service of humanity seems so full of a hubris missing in the wolf that kills the wild rabbit for food. Nonetheless, the evils of animal subjugation do not justify Singer’s position.

If he is only proposing the killing of babies with impairment as a consciousness raising tool to force acknowledgement of the philosophical inconsistencies that permit animal abuse, his method is egregious in its generation of suffering within the disability community. Its encouragement of those who devalue the lives of people with impairment is dangerous and inflammatory—monstrous in light of his declaration that pain is bad. If he makes his statements about infanticide out of genuine conviction, and the author believes he does, he operates from ignorance about the nature of lives lived with

¹¹³ Peter Singer, *Writings*, xv.

impairment and demonstrates a self-serving refusal to modify his position, even in the face of overwhelming testimony.

Would Singer assume the suffering, and advocate the annihilation, of a baby girl, born in a fundamentalist state, who, one might argue, will have a less powerful and more difficult life than her male counterpart, or assume the suffering, and advocate the annihilation, of a baby of color who will deal with entrenched racism sometime during his lifetime? Why single out babies with impairment for his patronizing assumptions? Singer uses the phrase “meaningful life” repeatedly throughout his many works. The author insists that the definition of “meaningful” is highly personal and for that reason, invalid when applied to another’s existence.

Robert Schalock, professor and chair of the department of Psychology at Hastings College and acknowledged expert in quality of life issues for people with cognitive impairment references a statement made originally by David Goode. He states, “Ultimately, it is how the individual perceives and evaluates his own situation rather than how others see him that determines the quality of life he or she experiences.”¹¹⁴

Edward Keyserlink, a Canadian professor and medical ethicist argues that quality of life should be, “...a notion purged of any trace of *relativizing human worth* and the lives of persons, or any hint of ‘social utility’ as a necessary qualification for treatment.”¹¹⁵ He also places the determination of what constitutes a quality life, in deciding termination of life issues, with the individual. He states:

¹¹⁴ Robert L. Schalock, ed., *Quality of Life: Perspectives and Issues* (Washington, D.C.: American Association on Mental Retardation, 1990), x.

...in the medical/health context, quality of life *need* not involve a comparison of *different human lives* as the basis for decisions to treat some and not others. Ideally, at the heart of quality of life concerns in this context should be only a comparison of the qualities *this patient* now has with the qualities deemed by *this patient* (or, if incompetent or irreversibly comatose, by the patient's agents) to be normative and desirable, and either still or no longer present actually or potentially.¹¹⁶

The author reiterates that only the individual and, in fact, only the non-coerced, pain-mitigated individual is in a position to determine whether his or her life is worth living. This is especially true because the experience of severe impairment is foreign to most people without impairment due to a history of isolation and exclusion.

Without personal experience, it is not possible to understand fully something that is difficult to articulate, but common within the disability community. There is a certain grace in acceptance of the challenges of life. Acknowledging difficulty, without a sense of justice denied and absorbing the information gleaned from the experience might lead to a type of satisfaction. While the author does not understand passive acquiescence to injustice and finds meaning in resistance to that which is unfair, he does insist that pleasure and pain have a self-defined aspect to them. Meaning can be derived from experiences, regardless of their initially perceived nature. Yet, Singer inserts his own individual perspective in making assumptions about the experiences of the other. He comments on the disappointments he assumes all parents experience when parenting a child with impairment, in this case Down syndrome:

¹¹⁵ Edward W. Keyserlingk, "The Quality of Life and Death," in *Quality of Life: The New Medical Dilemma*, ed. James J. Walter and Thomas A. Shannon (Mahwah, New Jersey: Paulist Press, 1990), 40.

¹¹⁶ Edward W. Keyserlingk, "Quality of Life," 40.

To have a child with Down syndrome is to have a very different experience from having a normal child. It can still be a warm and loving experience, but we must have lowered expectations of our child's abilities. We cannot expect a child with Down syndrome to play the guitar, to develop an appreciation of science fiction, to learn a foreign language, to chat with us about the latest Woody Allen movie, or to be a respectable athlete, basketballer or tennis player. Even when an adult, a person with Down syndrome may not be able to live independently; and for someone with Down syndrome to have children of their own is unusual and can give rise to problems.¹¹⁷

Not all parents experience dissatisfaction with the abilities of their child with impairment. In fact, experiencing a child's hard won mastery of a skill taken for granted in the non-impaired community is the categorical opposite of dissatisfaction. Renee Walbert, moderator of the listserv for Parent 2 Parent of Colorado writes:

My children are all grown now and so I do try to ask permission before sharing their stories, because they are their stories, not just mine. So with permission from our youngest daughter Deidra, I share this today.

Deidra is 22 and has many disability labels, including a vision and hearing disability and being a little person. Technically she is deaf/blind and practically, she looks like she is 12.

Today she did something for the first time. She is flying back to NYC today where she attends school at the Helen Keller National Center. Today for the first time, she went through security and got herself to her gate by herself.

This is not the first time she has flown alone. Last summer she was one of 2 delegates from Colorado to the National ADAPT Youth Summit in Chicago. She was 21 years old and I got a gate pass to walk with her down to the gate and waited till she got on the plane. My husband's cousin met her at the gate in Chicago when she arrived. Reversed the process with her uncle when she returned home. In July

¹¹⁷ Peter Singer, *Rethinking*, 213.

she attended the Little People of America convention in southern CA. Again, we walked her to check in and she met some other folks who were traveling to the convention that we knew and they helped her get where she was going, and cousins helped through the return process. In August she left to attend school in NY and I walked her to the gate, and folks from the school met her at the gate in NY. Same story when she came home for Christmas break. So she's had 4 round trips in this last year. It's not like she is a flying newbie...

Understand, when I share stories of my children's independence, some folks's response is, oh, well, they don't really have intellectual disabilities, they are high functioning (whatever that means!) Yes, they are independent, yes they do function very well. And yes, Deidra and Aaron both really do have intellectual disabilities. They easily qualified, meaning their IQ's are pretty low. But IQ just doesn't tell the whole story.

Their whole lives we have pushed them to be as independent as possible. And that has meant taking some risks. Risks in baby steps all along the way. It meant letting them go to the mall together and then alone, starting in late middle school, early high school when their peers also began learning those independent moves. It meant teaching them to ride a bus. Slowly, and with a lot of encouragement, but persistently.

It meant letting them try things on their own, assuring them, cheering them on, telling them they could do this, that they were amazing young people with lots of skills—even if we didn't necessarily believe it or trust that to be so! It meant when they got lost or something didn't go quite right making sure they knew how to use a cell phone or where to ask for assistance, helping them through it, not letting our own panic show in our voices, and then congratulating them on how even though they made a mistake or something went wrong, 'Look at how awesome you were! Look how you got through that. Look how we helped/someone helped you/you figured out...' whatever the circumstance warranted. It meant talking with them regularly, always about potential situations and asking them to think through, 'what would you do if....' and then helping them with possible choices if they couldn't project out what

they would do. Sometimes it meant practicing, sometimes it meant just sending them off and seeing if they'd fly or fall, sink or swim. Really, not all that different than the opportunities and encouragement that we gave our oldest daughter who didn't have an intellectual disability! That's part of parenting, helping them along the way. Giving them opportunities to practice...

So today my daughter is proud of herself and justifiably so. I walked with her to check her bag and then walked her down to security. But at security she kissed me goodbye, asked the gentleman standing there which line to walk through and headed up to TSA to start the process. I stood outside the barrier and watched her all the way through taking off her shoes, folding up her cane, taking her laptop out and placing everything in the bins and then walking up to wait her turn to go through the scanner. At that point I ran upstairs and I looked down to watch her finish the process (she'd already gone through the scanner) to wait till they told her she could get her things. I stood there watching while she set her boarding pass down on her backpack to put her shoes on thinking, 'don't forget your boarding pass, don't forget your id, don't forget your laptop, don't forget your cane!' Silly mommy, she did fine! She didn't forget a thing.

I watched her go down the escalator to the trains and then I left. I admit I did ask her to call me when she found her gate. I was on the road on the way home when my phone rang. Yes, she found her gate. I asked if a gate agent was there yet and she said no, but she'd asked a fellow passenger sitting there if this was the gate for LaGuardia and was told yes. And she asked the passenger to let her know if there were changes before a gate agent arrived since she couldn't see very well or hear announcements well. So I reminded her to tell the gate agent when s/he arrived that she would like to pre board and would need some assistance to find her seat. And then I asked her to call me when she was on the plane (hey I'm all for independence but I'm still a mommy!)

She just called me and not only is she proud of herself...I'm
PROUD OF HER!!!¹¹⁸

Frankly, in any case, the author finds objectionable Singer's premise that a child's worth depends on whether she fulfills preconceived parental notions of "acceptable" levels of ability or type of ability. Life might be lived with more contentment, with a relinquishment of entitlement or an expectation of the level of entitlement that must be delivered in order to stave off dissatisfaction. Is the avoidance of obvious manholes wrong? Not necessarily, but the author finds the contemplated killing of a child that even Singer describes as warm and loving, not suffering unduly, and with compensatory positive elements, as challenge avoidance in the extreme.¹¹⁹ In addition, making determinations as to the future nature of a newborn or his or her potential contribution seems impossible. As Johnson simply states, "Parenthood is in its essence a leap into the unknowable. When you eliminate a life of supposed suffering, you also eliminate the possibility of transcendence for that individual and for the people around him or her."¹²⁰

Jason Kingsley, author, musician, and artist, writes, in a high school essay, a response to the obstetrician who delivered him and who advised the Kingsley family to place him in an institution because he would never grow up to have a "meaningful thought." Jason says:

¹¹⁸ Renee Walbert, "Risk Taking, Building Self-Confidence, Building Pride" in Parent to Parent of Colorado [p2p-co@yahoo.com], posted 10 May 2012 [cited 27 May 2012]; internet

¹¹⁹ Peter Singer, *Rethinking*, 212.

¹²⁰ Harriet McBryde Johnson. "Unspeakable Conversations, or How I Spent One Day as a Token Cripple at Princeton University," in *Peter Singer Under Fire: The Moral Iconoclast Faces His Critics*, ed. Jeffrey A. Schaler (Peru, Illinois: Carus Publishing Company, 2009), 205.

He never imagined how I could write a book! I will send him a copy . . . so he'll know. I will tell him that I play the violin, that I make relationships with other people, I make oil paintings, I play the piano, I can sing, I am competing in sports, in the drama group, that I have many friends and I have a full life.

So I want the obstetrician will never say that to any parent to have a baby with a disability any more. If you send a baby with a disability to an institution, the baby will miss all the opportunities to grow and to learn . . . and also to receive a diploma. The baby will miss relationships and love and independent living skills. . . .

I am glad that we didn't listen to the obstetrician. . . . He will never discriminate with people with disabilities again.

And then he will be a better doctor.¹²¹

In attempting to debunk the contention, held by many, including those speaking above, in the disability community, that impairment is not a "lesser" position from which to lead life, Singer points out:

If disabled people who must use wheelchairs to get around were suddenly offered a miracle drug that would, with no side effects, give them full use of their legs, how many of them would refuse to take it on the grounds that life with a disability is in no way inferior to life without a disability? In seeking medical assistance to overcome and eliminate disability, when it is available, disabled people themselves show that the preference for a life without disability is no mere prejudice.¹²²

This comment seems to be beside the point to the author. Many people desire to, in their view, improve aspects of their lives with interventions like cosmetic surgery, the purchase of a bigger house, education, exercise, or dieting. Is the fact that they choose

¹²¹ Jason Kingsley and Mitchell Levitz, *Count Us In* (New York, New York: Harcourt Brace, 1994), 28.

¹²² Peter Singer, *Practical Ethics*, 54.

these “improvement” generating activities an indication that they perceive their lives to be “inferior” to people who are, without interventions, beautiful, able to effectively live in their dwelling, exposed to meaningful information and experience, fit, and thin? The choice to seek to improve one’s lot does not necessarily translate into feeling inferior to others. Improvement might be a purely self-generated absolute desire rather than a relativistic one. There are people with impairment who choose to seek a “cure” and those who do not. The author will leave individual choice and individual considerations to the individual. Singer, however, in additional statements, questions the validity of self-reported contentment with quality of life among people with impairment:

Since we are dealing only with reported happiness levels, however, it is possible that, as (professor of economics, Tyler) Cowen suggests, people with severe disabilities ‘adjust their expectations’ or ‘lower their aspirations in life.’ They may then be reporting how well their life meets their expectations, and this could make it misleading to use their reports to compare their idea of happiness to that of people with normal expectations. The third reason for doubting that the studies show what (professor of philosophy, Harry) Gensler claims they show is that the method they use—obtaining people’s own reports of how happy they are—skews the sample of people with disabilities, since it omits those who have intellectual disabilities severe enough to prevent them understanding the question they are being asked.¹²³

The author would like to assert that any individual’s sense of contentment exists within the matrix of their experienced life. Would Singer question the validity of a response that life is well worth living from a refugee in Darfur, with the dismissive comment, “But they have no idea what it’s like to live in America?” Rich or poor,

¹²³ Peter Singer, “Reply to Harriet McBryde Johnson,” in *Peter Singer Under Fire: The Moral Iconoclast Faces His Critics*, ed Jeffrey A. Schaler (Peru, Illinois: Carus Publishing Company, 2009), 207-208.

confident or fearful, educated or unschooled—it is elitist to make assumptions about the validity of another’s perspective. Furthermore, would Singer find it equally easy to euthanize a smiling, cooing baby as a baby screaming in obvious distress? If non-verbal signals are invalid indicators of misery or contentment, there should be no moment of question, no human hesitation. Anyone who knows a person with severe cognitive impairment knows when that person is content. While utilitarians may find it impossible to quantify happiness in non-verbal people, the author finds the quantification of such ephemeral states as happiness or contentment invalid in any case, in so much as such states derive from the internal perspectives of individuals and are based on individually derived criteria that cannot be reflected in any standard survey.

It must also be noted that professionals, or parents under the influence thereof, often coerce decisions on active treatment of impairment instead of medical intervention being a choice, instigated by the person with impairment themselves. In addition, there is an elusive perspective that the author sometimes gets a glimpse of, which promises peace through a certain sort of surrender. Not surrender to injustice, rather surrender to the nature of life. This is not a perspective solely found within the disability community, but evident in many who have experienced challenges. If individuals approach life like a game of paintball, where each new challenge must be thwarted by constant vigilance and where, if one is “hit,” the game is lost, a state of constant stress and discontent prevail. Without doubt, all individuals will be “hit” no matter the degree of attention and constant caution maintained. For the author, it is better to proceed with good intentions and fellow feeling, with thought-through choices and whatever wisdom one can muster, rather than proceed with fear and rigid expectations. Is disappointment inevitable from time to time?

Yes, but one can, at least, choose to escape a state of self-indulgence that leads to omnipresent dissatisfaction and a constant maintenance of high alert that leaves little opportunity for creative solutions and growth.

The author asserts that many in society, like Singer, fail to completely observe and accurately understand people with impairment. Their initial perception is that the person is different and lacks some valued aspect of being human. Upon closer evaluation, it would become clear that many other aspects of the person's life are flourishing and that, overall, the person with impairment is an amalgam of happiness and pain, strength and weakness, contribution and need, as is any human being. Having grown up insulated from people with severe impairment, however, the able observer has pre-programmed misconceptions and the fears they engender. This truncates one's observational capacity.¹²⁴

Fear of Difference, Avoidance, and the Legacy of Isolation

Our very human essence is so damned undignified and so uncontrollable. We spend most of our life working like fiends to maintain the illusion that we are in control, that we can tame and tidy nature. Let's face it: nature always has the last laugh. Nowhere does the old girl laugh louder than with disability and death. God forbid we human beings should ever have to get up close and personal with our unwieldy, messy, smelly humanness. In every way possible, this culture's rules and values distance us from the realities of our own bodies in all their glorious imperfection.--Cheryl Marie Wade, Thoughts on the "Right to Die with Dignity" for Ragged Edge Magazine

¹²⁴ For a discussion on mindfulness and mindlessness in the observers, see: Ellen J. Langer and Ben Zion Chanowitz, "Mindfulness/Mindlessness: A New Perspective for the Study of Disability," in *Attitudes Toward Persons with Disabilities*, ed. Harold Yuker (New York, New York: Springer Publishing Company, 1988), 79.

When contemplating a life lived with impairment, the non-impaired observer might envision *his* life in an impaired body and mind, a position assumed to be necessarily outcast, burdensome, and non-productive, without redeeming positive characteristics. He may fear becoming the object of the pity and revulsion *he* experiences when encountering those with impairment. What is unnerving about encounters with people with severe impairment that leads to avoidance, sequestration, the consequent lack of familiarity and the misunderstandings these engender? What must occur for society to experience a desire for integration? Many factors lead to fear and aversion; many are long established and present strong resistance to change.

When the inexperienced individual meets a person with impairment, which includes learning disabilities or other conditions that involve a deficit of theory of mind, he is immediately on unfamiliar and uncomfortable ground. Theory of mind involves the ability to understand the mental states of others, including their intentions, desires, beliefs, and emotions without their verbal input. When interacting with someone who is theory-of-mind-deficient, one experiences a certain lack of acknowledgement. Lack of or impaired theory of mind occurs in, among a variety of impairments, autism and non-verbal learning disabilities. How is one to act when his relational counterpart violates personal space, does not make eye contact, or cannot ascertain when a topic has outlived the listener's interest? Human interaction depends in large part on the unconscious processing of social cues. If this skill is impaired and interaction with the other results in confusion, the uninitiated individual wants to escape to familiar ground where one can

expect one's communication partner to behave "appropriately," reading one's needs and desires, without verbal instruction.

Another, yet related, discomfort accompanies the non-impaired person's interaction with someone who is cognitively or communicatively impaired. In the person with intellectual impairment, mental illness, or poor verbal abilities, a lack of expected rationality or an inability to demonstrate rationality expressively, means that conventional expectations for behavior are futile and the uninitiated individual experiences anxiety. "Will this person touch me?" "Will she draw attention to me?" "What does she want?" "What should I do?" The unimpaired individual can become so anxious that staying present becomes impossible.

While problems arise from an inability to perceive and honor the unspoken needs and desires of a conversation partner and from a lack of expected rationality, to have one's physical appearance or movement offend the other is to lead just as segregated and marginalized an existence. People without impairment, who have little exposure to human differences, are frequently uncomfortable meeting the eyes of someone who utterly fails to comply with socially and culturally valued norms and customs that hinge upon physical integrity, beauty, and health.¹²⁵

Society rewards physical perfection and athletic achievement with popularity. It punishes non-compliance with shunning and isolation. Children, who lack social graces, stare with curiosity. Adults, uncomfortable with the rudeness of staring and the act of

¹²⁵ Hanoch Livneh, "A Dimensional Perspective on the Origin of Negative Attitudes Toward Persons with Disabilities," in Harold Yuker, ed., *Attitudes Toward Persons with Disabilities* (New York, New York: Springer Publishing Company, 1988), 36.

questioning, attempt to appear at ease, but escape as soon as possible. Lezlie Frye, a slam poet who addresses this phenomenon, dressed in sleeveless black to accentuate her asymmetrical hands, raps:

Don't stare here
Fix your eyes on your fear
Check yourself
Inspect yourself for
Whatever it is that's so alarming
That you won't look me in the eyes stop
Telling me lies
About who I am

Look I can feel it when we meet
Inside, discomfort
Outside, grin
It's confusing these two faces
Digesting my image...
And how I feel is tired.¹²⁶

Yet, if a “normal” interaction is desirable and necessary to integration, what are the lookers to do about their, as Susan Sontag in her 2003 book *Regarding the Pain of Others* calls, “repulsive attraction.” “Staring is an ocular response to what we don’t expect to see. Novelty arouses our eyes. More than just looking, staring is an urgent eye jerk of intense interest.”¹²⁷ People need to understand and try to order that which is non-compliant with their ingrained sense of correctness. Regular exposure to human variance will lessen, and eventually dispel, the shock initiated by difference, but is there more to the escape impulse?

Rosemarie Garland Thomson, a disability historian states:

¹²⁶ Lezlie Frye, “Don’t Dis- My Ability,” in Rosemarie Garland-Thomson, *Staring: How We Look* (New York, New York: Oxford University Press, 2009), 138.

¹²⁷ Rosemarie Garland Thomson, *Staring: How We Look* (New York, New York: Oxford University Press, 2009), 3.

...viewed from the perspective of...the *normate*, disability has always been the object of a negative comparison to what is typically construed as corporeal normality.¹²⁸ The attitudes that have historically attended people with disability have varied over time, but reiterated in all epochs is the idea that they carry an excess of meaning and therefore offer an insistent invitation to a series of interpretative...framings.¹²⁹

Children's books throughout the ages have invented the dwarfish troll, or the deformed ogre, the pirate with a patched eye and wooden leg, the hunched back witch, and Peter Pan's nemesis, Captain Hook. They have conflated disability with depravity and evil. In a similar way, society focuses hatred on a symbol and when marginalized, that symbol becomes a "scapegoat."

The initial concept of the scapegoat appears in the Bible in Leviticus 16:20-22:

And when he hath made an end of reconciling the holy [place], and the tabernacle of the congregation, and the altar, he shall bring the live goat:

And Aaron shall lay both his hands upon the head of the live goat, and confess over him all the iniquities of the children of Israel, and all their transgressions in all their sins, putting them upon the head of the goat, and shall send [him] away by the hand of a fit man into the wilderness:

And the goat shall bear upon him all their iniquities unto a land not inhabited; and he shall let go the goat in the wilderness.¹³⁰

¹²⁸ According to Rosemarie Garland Thomson, "Normate...is the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them." See Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York, New York: Columbia University Press, 1997), 8.

¹²⁹ Ato Quayson, *Aesthetic Nervousness: Disability and the Crisis of Representation* (New York, New York: Columbia University Press, 2007), 4.

¹³⁰ Lev. 16:20-16:22 KJV.

Here, a priestly individual invests an animal with all of society's evils and banishes it into the wilderness, leaving in its wake a ritually cleansed community.

Historically, the identification of a human scapegoat, an individual who symbolizes a community's ills and evils, has fallen upon the ugly, ill, different, taboo, and outcast. The exile of the scapegoat renders the village free of "contagion" for a period. In Wole Soyinka's 1967 play *The Strong Breed*, the ritual scapegoating, called *egungun* in Yoruba, of a boy with cognitive impairment, is to take place in an effort to cleanse the tribe of impurity and contagion. The tribe chooses Ifada, because of his disability, to be the ritual carrier of the village's ills, which will disappear with the boy upon his expulsion.¹³¹ Modern society exiles people with impairment with scapegoating behavior as well. For a variety of reasons, it reviles and exiles to the margins people with both severe physical and intellectual impairment.

Andrew Kania, theologian and director of spirituality at Aquinas College at Manning in Australia suggests that it is fear that drives scapegoating:

In the end, if a person is to be known, (according to the adage) for the friends and the enemies that he or she makes, should not yet another criterion be made, that he or she should be known by the scapegoats they create? For a simple equation does exist that whoever bears the brunt of our 'scapegoatism' must in some way serve as an indicator as to a particular deficiency that exists deep within ourselves...The fundamental drive of scapegoatism is thus a strong sense of being threatened...Thus the individual we seek to scapegoat is in reality a distorted mirror of all we most despise of in ourselves; they look back at us — peering deep into that part of our ego, that is insecure, incompetent and frightened. They seem to know us, more

¹³¹ Ato Quayson, *Aesthetic Nervousness*, 121-122.

than we wish to be known — they seem to know the extent to which we lie and the extent to which we tell the Truth.¹³²

Could this be because they expose to us some hidden compartment, individual or collective, where fears lie buried and boogiemen abound? Could the investigation, understanding, and excision of these psychic infections lead to greater health and wellbeing and, if this is true, could people with impairment prove to be valuable magic looking glasses that deliver, if only one allows them to, insight and healing?

Julia Kristeva recognizes this phenomenon and refers to the impaired body as a generator of ontological anxiety—a reminder that “the clean and proper body” is transient and uncontrollable. She uses the term “abject” for all states, which a person must deny in order to continue the comforting yet fraudulent expectation of undisturbed perfection.¹³³

Tobin Siebers, a disability theorist at the University of Michigan, in discussing the ontology of the Ugly Laws (statutes in many major American cities from 1867 to 1974 that targeted the confluence of impairment and poverty by making “unsightly” begging illegal) discusses a “primordial obsession with perfect, public bodies.”¹³⁴ Edward Slavishak writes about prosthetic limbs, popular during the period of endemic industrial accidents at the turn of the twentieth century, which manufacturers advertised as

¹³² Andrew Thomas Kania, “The Scapegoat,” *Catholica*, August 12, 2008, http://www.catholica.com.au/andrewstake1/087_ak_120808.php

¹³³ Julia Kristeva, *Powers of Horror: An Essay on Abjection* (New York, New York: Columbia University Press, 1982), 1, 8, 71.

¹³⁴ Tobin Siebers, “What Can Disability Studies Learn from the Culture Wars?” *Cultural Critique* 55 (2003): 198.

camouflage for the “unsightly” and “embarrassing” impaired body.¹³⁵ Displayed impairment makes one outcast, for if the unimpaired person accepts an individual with physical or cognitive impairment as a normal variance within the human condition, it holds that she must accept the possibility or even the inevitability of also becoming impaired—be it by disease, accident, or age. Many “typicals” in society push people with impairment into the margins—see them as social outcasts, economic burdens, and moral pariahs for all of the above reasons. They pretend that they will never join the ranks of those with impairment. They refuse to investigate individual and cultural disease triggered by interaction. Yet, they are aware subconsciously of the lack of justice involved in such behavior. Ambivalence, between compassion and sympathy, on one hand and aversion and distaste on the other, triggers “intense feelings of guilt and anxiety” that affect self-esteem. Thus, the non-impaired observer feels the need to get away from or denigrate the individual with impairment (thus removing the sympathy factor).¹³⁶ If the person with impairment can be kept at arm’s length, responsibility surrounding possible duties and obligations owed to that individual, triggered by guilt over the unjust nature of the relationship, can be ignored. A transcript of Chicago’s 1881 version of the so-called Ugly Laws states:

Any person who is diseased, maimed, mutilated, or in any way deformed, so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets, highways, thoroughfares, or public places in this city, shall

¹³⁵ Edward Slavishak, “Artificial Limbs and Industrial Workers’ Bodies in Turn-of-the-Century Pittsburgh,” *Journal of Social History* 37, no. 2 (Winter 2003): 372.

¹³⁶ Hanoch Livneh, “A Dimensional Perspective,” 37.

not therein or thereon expose himself to public view, under the penalty of a fine of one dollar for each offense.¹³⁷

Such visceral verbiage exposes the lengths to which people were willing to go to avoid the feelings triggered by an encounter with a person with impairment. Archaic though the Laws seem today, the discomfort engendered by impairment is still alive and well in the human psyche, including the deep-seated acculturation of many people with impairment themselves who, if they have not done intensive work to free themselves, carry the burden of both society's prejudices and their own internalized judgments. Here, too, in the language of the Chicago Ugly Laws one can detect a whiff of the notion of contagion linked with impairment discussed above as scapegoating. Martha Nussbaum discusses the implications of identifying something or someone as *disgusting*,

This act (or, more often and usually inseparably, this person) is a contaminant; it (or he or she) pollutes our community. We would be better off if this contamination were kept far away from us.¹³⁸

When society dismisses, sequesters, avoids, and denies the right to participate to “different” individuals, communities fail to experience their reality or value. Rights that promote equal participation, as well as bodily integrity, exist to mark the arenas, agreed upon by society, which are sacrosanct in their essentiality to a minimally decent human life for everyone, including those people with impairment. Historically, political theory, including contemporary human rights theory, links rights to human characteristics, which define the qualifier—personhood.

¹³⁷ Susan M. Schweik, *The Ugly Laws: Disability in Public*, (New York, New York: New York University Press, 2009), 1.

¹³⁸ Susan M. Schweik, *Ugly Laws*, 94.

Chapter Three

Reasonably Confused: Human Rights and Cognitive Impairment

*Plato had defined man as an animal, biped and featherless, and was applauded. Diogenes plucked a fowl and brought it into the lecture room with the words, 'Here is Plato's man.' In consequence of which there was added to the definition, 'having broad nails.'—Diogenes Laertius, *Lives of the Eminent Philosophers**

In a conversation the author had in 2008 with Laura Hershey, friend, disability rights activist, and participant in the United Nations Convention on the Rights of Persons with Disabilities (CRPD), he brought up the problem of rights, personhood, and rationality. The author wanted to know why, when the working group, of which she was a member, designed the CRPD, they did not explicitly address a redefinition of the notion of personhood to describe the status of all human beings, without consideration for reasoning ability. Hershey was surprised that the author would suggest any implicit exclusion existed in previous documents or that people without the ability to reason currently hang in limbo within important primary human rights documents and political theory in general. Her understanding was that the Universal Declaration of Human Rights (UDHR), true to its name, was universal in its scope and that the CRPD followed in its sentiment.

Unfortunately, for her view, much of political theory, from that of Socrates to Rawls and, in current human rights theory, contributors including Donnelly, Gewirth, and Pettit, has conflated rationality with recognition and inclusion in the political system. The UDHR, as the primary document of human rights theory, is seemingly irreconciled on the status of people with severe intellectual impairment and therefore not clearly universal in its application. The language is conflicted, leaving unaddressed questions. What does the term *human* mean? Does *everyone* really mean everyone? Is there a difference between *human being* and *person*?

Within human rights language, one understanding of the meaning of “human,” in contention with other more reason-centric conceptions, assumes, as did Hershey, that it describes those who simply share the DNA of *Homo sapiens*. The Universal Declaration of Human Rights considers members of the “human family” beneficiaries of rights. In the preamble, it states, “Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice, and peace in the world...” What, however, does the term “human family” mean? Later in the Declaration, in Article 1, it states, “All human beings are born free and equal in dignity and rights. They are endowed with *reason and conscience* and should act towards one another in a spirit of brotherhood.” Article 2 states:

Everyone is entitled to all the rights and freedoms set forth in the Declaration, *without distinction of any kind*, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or *other status* (all italics the author’s).

If the intention is to be fully inclusive, the ambiguity as to what constitutes a human in this primary human rights document is frustrating.

The Convention on the Rights of Persons with Disabilities, assuming, the author believes, that there is no confusion in the UDHR and ignoring a history of exclusion in political theory, fails to clarify the term “persons.” Unfortunately, while it does not specifically refer to rationality as the defining human characteristic, it does refer to itself as a supplement to the UDHR, which does, both in the above assumption that all humans have rationality and later, in Article 29, Section 1, where it states that all recipients of human rights must perform duties (which require reason to understand and undertake). When researching discussion minutes and reports published by working groups for the major human rights documents, as well as committees clarifying the documents and reporting on their implementation, the author found no actual grappling with the historical problem of rationality and personhood. Instead, he found an approach, which assigns rather than debates definitions. Several instances affirm that the term “disability” in the CRPD is inclusive of cognitive or intellectual impairment. The Human Rights Council and the United Nations High Commission for Human Rights say,

Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”¹³⁹

In agreement with this definition, the Network of African National Human Rights states, “Thus disability is a phenomenon, reflecting an interaction between features of a person’s

¹³⁹ Human Rights Council. 2007. *Implementation of General Assembly Resolution 60/251 of 15 March 2006 Entitled “Human Rights Council*. Jan. 17, 2007 (A/HRC/4/75), 7. Available online through <http://documents.un.org/> and Human Rights Council. 2009. *Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary-General. Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities*. Jan. 26, 2009 (A/HRC/10/48), 12. Available online through <http://documents.un.org/>

body and features of the society in which he or she lives...Such impairments may include physical, sensory, and cognitive or intellectual impairment.”¹⁴⁰ Many documents also exist, which deal with the implementation of specific rights for persons with impairment enumerated in the CRPD, the Convention on the Rights of the Child, and the Convention on the Elimination of All Forms of Discrimination against Women, including voting, education, due process, health-care, property, expression, and reproductive rights—all as pertain to people with intellectual impairment.¹⁴¹

Considering the obvious intent in secondary human rights documents to include people with intellectual impairment, the author must conclude that despite the reference in the UDHR claiming that reason and conscience are universal human traits, this is more a statement of the potential for human compassion and dignity than a statement of criteria for personhood or participation. If the terms “human family” or “human” in documents pertaining to human rights refer to all *Homo sapiens*, as Hershey believed, this definition offers rights-bearing status to people with severe intellectual impairment, as there is no

¹⁴⁰ Human Rights Council. 2010. *Written Contribution by the Network of African National Human Rights Institutions to the Panel on national frameworks under article 33 of the Convention on the Rights of Persons with Disabilities*. Feb. 24, 2010. (A/HRC/13/NI/8), 2. Available online through <http://documents.un.org/>

¹⁴¹ UN Convention on the Rights of Persons with Disabilities. 2009. *Committee on the Rights of Persons with Disabilities, Second Session, Summary record of the 6th meeting* held at the Palais des Nations, Geneva, on Wednesday, 21 October 2009. (CRPD/C/2/SR.6), 4, 5. Available online through <http://documents.un.org/>; Committee on the Rights of Persons with Disabilities. 2011. *Implementation of the Convention on the Rights of Persons with Disabilities: Initial reports submitted by States parties under article 35 of the Convention: Hong Kong, China*. Feb. 11, 2011. (CRPD/C/CHN-HKG/1), p. 65, 89 and Convention on the Rights of the Child. 2007. *General Comment No. 9 (2006); the Rights of Children with Disabilities*. Feb. 27, 2007. (CRC/C/GC/9), 12. Available online through <http://documents.un.org/> and Secretary General of the United Nations. 2009. *Right of everyone to the enjoyment of the highest attainable standard of physical and mental health*. Aug 10 2009. (A/64/272), 19 and Committee on the Elimination of Discrimination Against Women. 2010. *Consideration of reports submitted by States parties under article 18 of the Convention on the Elimination of All Forms of Discrimination against Women: 5th periodic report of States parties: Israel*. Mar 24, 2010. (CEDAW/C/ISR/5), 23, 27. Available online through <http://documents.un.org/>

criterion of rationality. This approach does universalize human rights theory, but, unfortunately, conferring personhood in this way might not adequately promote the goal of full acceptance and integration necessary for substantive rights acquisition.

Because the criteria for membership in this model are undefined, this understanding fails to explain what about a human (assuming this is not limited to rationality and the traits it engenders) is valuable. Generalizing by fixed categories (human being) assigns rather than observes value and so does not adequately contribute to the notion that people with intellectual impairment are valuable members of society, only that they are human and, as such, worthy of rights. Defining a person in terms of valuable human attributes seems necessary, but limiting who is valuable based solely on the ability to reason is exclusionary.

Making choices and understanding one's ends and the best means for their achievement requires reason and defining political participants or "persons" as rational choosers has historically been a basic notion of most theory. The requirement of rational capability clearly excludes people with severe intellectual impairment and finding additional human characteristics to augment previous notions of personhood seems a worthy goal. This achieved, people with severe intellectual impairment might find acceptance within the human family instead of their human rights status, without defined value, leading to the mantle of *burden*. Law may mandate rights, but the feeling of receiving goods grudgingly as an imposed obligation is not optimal. For people with severe intellectual impairment to be included as rights-bearers because one's contribution (even if lacking intent) is valued would lead instead to goods that cannot be mandated, including genuine substantive inclusion. The profound difficulty of this challenge lies, in

part, in the stature of the proponents of ratio-centrality, its long standing supremacy, and the appropriate veneration of the potential of human reason. What would be the consequences if this monolithic structure is found wanting? Due to these impediments, even if the documents aim for universality, people with severe intellectual impairment hold morally ambiguous status within rights models and the singular importance of reason persists for most rights theorists.

Some theorists conceive human rights as catalytic in the fulfillment of human potential in that they clear the way for chosen action to advance and provide a template for moral development. Humans who interact within a rights structure are encouraged by a united human consensus on basic social practices to choose socially beneficial actions.

As Kant notes:

The concept of right, insofar as it is related to an obligation corresponding to it (i.e., the moral concept of right), has to do, *first*, only with the external and indeed practical relation of one person to another, insofar as their actions, as deeds, can have (direct or indirect) influence on each other.¹⁴²

According to Jack Donnelly, Andrew Mellon Professor of International Studies at the University of Denver, human rights are a “prescriptive moral account of human possibility.”¹⁴³ He continues:

Just as an individual’s ‘nature’ or ‘character’ arises from the interaction of natural endowment, social and environmental influences, and individual action, human beings create their ‘essential’ nature through social action on themselves. Human rights provide both a substantive

¹⁴² Immanuel Kant, *The Metaphysics of Morals*, ed. and trans. Mary Gregory (New York, New York: Cambridge University Press, 1996), 23-24.

¹⁴³ Jack Donnelly, *Universal Human Rights in Theory and Practice*, 2nd ed. (Ithaca, New York: Cornell University Press, 2003), 14.

model for and a set of practices to realize this work of self-creation.¹⁴⁴

Does Donnelly intend the scope of his human rights model to include people lacking the ability to self-create—seemingly an act that requires intent? Does he believe that human rights bearers *must* be able to claim rights? He says, “...the ability to claim rights, if necessary, distinguishes having a right from simply being the (rights-less) beneficiary of someone else’s obligation.”¹⁴⁵ The long-standing charity model of goods-delivery to people with severe impairment seems to fall within this description.

Per Donnelly, the rights-bearing citizen also holds duties.¹⁴⁶ Article 29, Section 1 of the UDHR states, “Everyone has duties to the community in which alone the free and full development of his personality is possible.”¹⁴⁷ Can a person, lacking reasoning ability, understand these obligations and choose to perform them? The answer seems to be that they cannot and so, lacking an ability to perform classical duties intentionally, people with severe intellectual impairment remain non-participants. If the actual intent of the UDHR is to be fully inclusive, the word “contributions” should replace the word “duties” and society must consider whether it is necessary that intent accompany contribution.

Donnelly’s comment that rights are “*universal*” and that “we consider all members of the species *Homo sapiens* ‘human beings,’ and thus holders of human rights”

¹⁴⁴ Jack Donnelly, *Universal Human Rights*, 15.

¹⁴⁵ Jack Donnelly, *Universal Human Rights*, 9.

¹⁴⁶ Jack Donnelly, *Universal Human Rights*, 25.

¹⁴⁷ Universal Declaration of Human Rights, Article 29, Section 1, December 10, 1948, 217A(III), available at <http://www.un.org/en/documents/udhr/index.shtml>

appears to be in contradiction with his discussion of issues of self-creation, claiming, and the performance of duties.¹⁴⁸ The latter statements seem to lead to the conclusion that he sees no opening for people with severe intellectual impairment. If this second interpretation is correct, it may be based on Donnelly's intended position or it may be an artifact of the lack of attention paid by the community of human rights theorists to the tension between claims of universality and continued reliance on actions, which require the exercise of reason.

Alan Gewirth, Professor of Philosophy at the University of Chicago, conflates rationality with rights-bearing status, though he leaves an opening for partial status. He maintains that human rights are created to guard "the freedom and well being which are respectively the procedural and substantive necessary conditions" that allow for *purposive* human action.¹⁴⁹ He continues:

All the human rights, those of well being as well as of freedom, have as their aim that each person have rational autonomy in the sense of being a self-controlling, self-developing agent who can relate to other persons on a basis of mutual respect and cooperation, in contrast to being a dependent, passive recipient of the agency of others. Even when the rights require positive assistance from other persons, their point is not to reinforce or increase dependence but rather to give support that enables persons to be agents, that is, to control their own lives and effectively pursue and sustain their own purposes without being subjected to domination and harms from others.¹⁵⁰

¹⁴⁸ Jack Donnelly, *Universal Human Rights*, 10.

¹⁴⁹ Alan Gewirth, *Human Rights: Essays on Justification and Applications*, (Chicago, Illinois: University of Chicago Press, 1982), 4.

¹⁵⁰ Alan Gewirth, *Human Rights*, 5.

In this statement, Gewirth posits a continuum of rationality and capability of self-determination, leading to the consideration of degrees of rights. His linkage of human rights and purposeful action replaces the idea of equal distribution of rights and their universality with the “Principle of Proportionality.”¹⁵¹ Per Gewirth:

All humans have the human rights in full to the extent that they are inherently capable of exercising them. This inherent capacity pertains to each human so long as he is a rational agent in the minimal sense of having purposes he wants to fulfill and being able to control his behavior accordingly while knowing the particular circumstances of his action.¹⁵²

The author understands this statement to imply that there are degrees of personhood (in the traditional meaning of the word, wherein rationality remains the singularly defining element) and therefore degrees of rights-bearing status. This position exists in the status of a ward under limited guardianship where the guardian has only those powers granted by the court, based on limited areas of incapacity in the ward, rather than complete powers. Others agree that traditional personhood may exist in degrees.

Philip Pettit, Laurance S. Rockefeller Professor of Politics and Human Values at Princeton University, defines a *person* as someone who, while engaged in discourse, can maintain an independent position, free of coercion.¹⁵³ The author understands Pettit’s notion of a free individual to be one who merits moral consideration and rights. Pettit says:

¹⁵¹ Alan Gewirth, *Human Rights*, 8.

¹⁵² Alan Gewirth, *Human Rights*, 8.

¹⁵³ Philip Pettit, *A Theory of Freedom: From the Psychology to the Politics of Agency*, (New York, New York: Oxford University Press, 2001), 70.

Freedom in the agent...has three aspects. It covers, first, the freedom of the action performed by an agent on this or that occasion; second, the freedom of the self implicit in the agent's ability to identify with the things thereby done, rather than having to look on them as a bystander; and third, the freedom of the person involved in enjoying a social status that makes the action truly theirs, not an action produced under pressure from others. So construed, freedom in the agent has a social as well as a psychological aspect...¹⁵⁴

The author sees "the freedom of the self" as descriptive of the "rational," "the freedom of the action" as descriptive of the "chooser," and "the freedom of the person" as descriptive of a human in a social context maintaining autonomy under conditions of coercion. Pettit clarifies:

To predicate freedom of an agent, in particular of something an agent did, is to suggest that at least three different sorts of things hold. The first is that an agent can be rightly held responsible for what he or she did; if the action was free then there can be nothing against thinking that the agent should have to answer for it. The second is that the action freely chosen is one that the agent can own, thinking: this bears my signature, this is *me*. And the third is that the agent's choice was not fully determined by at least certain sorts of antecedents...¹⁵⁵

Like Gewirth, he posits that there might be degrees of "fitness to be held responsible."

Pettit states:

...freedom as we ordinarily conceive of it can come in degrees or be missing completely. We may think that someone is not responsible for anything—is not a responsible agent—or is not responsible in any sense for a certain action, or is responsible but only in diminished measure, or is responsible but under mitigating

¹⁵⁴ Philip Pettit, *Theory of Freedom*, 4.

¹⁵⁵ Philip Pettit, *Theory of Freedom*, 6.

conditions... We may think that an agent, say someone out of their mind, is not free in any sense... Or we may think that the freedom of an agent to choose that option was reduced but not entirely removed, whether by virtue of diminished capacity or mitigating circumstances.¹⁵⁶

Though Pettit posits that, due to a continuum of capacity for “fitness to be responsible,” a large percentage of people with intellectual impairment qualify for his concept of personhood status, he is seemingly uncomfortable with excluding the percentage who remain outside of consideration. He states,

Babies and some other human beings may not actually have this ability but they can count as persons and selves in the extended sense that they share a common nature—our nature as humans—with those who can.”¹⁵⁷

To the author, this statement ineffectively evades the fact that “proper fitness to be responsible” cannot be a fully inclusive requirement for rights-bearing status. By his aside, which deviates from his overall position, Pettit seems to acknowledge the unacceptability of excluding even a small portion of the human family from rights practice, but his solution seems cursory. He needs to clarify what constitutes “our nature as humans” and if “babies and some other human beings” are persons, what aspects of their nature, beyond rationality, pertain.

The author has been questioned on two fronts. The first is in the assumption that participation necessarily leads to rights. The second is in the assertion that participation of any kind is of equal value, and leads to equal substantive rights. Certainly, in real-world scenarios, communities of people neither afford rights to all participants, nor are

¹⁵⁶ Philip Pettit, *Theory of Freedom*, 21.

¹⁵⁷ Philip Pettit, *Theory of Freedom*, 80.

non-hierarchical in their valuing of contribution. States, in which slavery exists, deny rights to slaves despite the economic value of their contribution. Around the world, women's contributions are assigned a relatively lower value in the hierarchy of contribution and caste systems distribute substantive rights based on birth status without regard for either quality or amount of participation. Yet, the intent of justice as fairness is not to describe the extant state of freedom and justice, but to provide a template for a "realistic utopia." In a Rawlsian construct, designers, veiled from their individual circumstances, are expected to choose to design a society under the constraints of the two principles of justice. The lexically prior principle of equal liberty states that "each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all." This principle is predicted based on the assumption that designers will desire a system of substantive democracy where, even if unequal natural talents lead to somewhat unequal acquisition of economic goods, an unequal distribution of basic liberties would be unacceptable. A Rawlsian system of justice has no place for systems of exploitation, caste, or patriarchy.

If it is asserted that people contribute to their society unevenly and that someone who contributes without intent or work, should not enjoy the same level of rights as the great composer, statesman, scientist, or innovator, the author asks, "Who will make the determination of what is more or less valuable?" These elite decision makers would either represent the interests of the powerful or the interests of the majority. Neither scenario is compatible with a Rawlsian vision. In the original position, there would be no

hierarchy of designers and while majority rule might hold sway at a constitutional or legislative level, it could never override the principles of justice.¹⁵⁸

The author acknowledges that one can only enjoy freedom, as in the goal of human rights, to the degree that the capacity for enjoyment exists; however, society must afford everyone equal human rights without regard for rationality. There is a difference between withholding rights because a judgment exists that one is not within some definition of personhood and affording rights, without prejudice, which one can then enjoy as his abilities and associations (support systems) allow. In order to expand useful associations, people with severe intellectual impairment must achieve the status of valuable citizens. Theory need not abandon the notion that a criterion delineates socially valuable players, only that what is considered valuable utilize a larger definition of contribution than rationality alone. For the sake of clarity, this work will define a contribution as an act that furthers the social good of human fulfillment. One might contribute consciously or, as this work purports, without intent. What sorts of contribution, beyond the conscious fulfillment of duties, is necessary for human flourishing? The author asserts that among these, the affective bonds of relationship are essential and possible without intent.

Richard McCormick, professor of bioethics at Georgetown University, in discussing the nature of personhood, suggests that this is the case, stating, “The meaning, substance, and consummation of life is found in human relationships...life is a value to

¹⁵⁸ John Rawls, *A Theory of Justice*, 313.

be preserved only insofar as it contains some potentiality for human relationships.”¹⁵⁹

The author welcomes a relational option for defining personhood, and points out that relationship generally exists between a parent and his or her severely intellectually impaired child—even one so impaired as to only acknowledge the parent with a smile. Certainly, many people who lack rationality, but are abundantly able to express emotion can reciprocate relationship. People with intellectual impairment might be empathetic, playful, trusting, and loving.

A second variety of extra-rational contribution exists in the joy felt when another reflects our own human appreciation for beauty, such as exquisite musical harmony. Humans need to “share a moment” or find common ground with others. When professor Kittay listens to Beethoven’s “Ode to Joy” with her severely intellectually impaired daughter, Sesha, and describes Sesha’s radiance as “excitement of her entire soul,” is her observation affected by the human bond she feels when her daughter’s reaction to beauty mirrors her own?¹⁶⁰ If so, does Sesha’s reaction enrich her mother’s experience? It is an amazing thing that humans generally agree on what is beautiful. When humans share an experience, that sharing affirms connection, affirms collaboration in something larger than self. Experiences of beauty, while sometimes having an intellectual element to them, are predominantly emotional in nature. Thus, Kittay’s joy in seeing Sesha enraptured by Beethoven demonstrates Sesha’s contribution to her mother’s flourishing. Could it be that experiencing common reactions to beauty, or even to ugliness, with

¹⁵⁹ R.A. McCormick, “To Save or Let Die: The Dilemma of Modern Medicine,” in *Quality of Life: The New Medical Dilemma*, ed. James J. Walter and Thomas A. Shannon (Mahwah, New Jersey: Paulist Press, 1990), 30, 32.

¹⁶⁰ Eva Feder Kittay, *Love’s Labor*, 151.

another human being helps to remove one's sense of "specialness and separateness?"¹⁶¹

Can this encourage community?

The author thinks that a person's value and contribution stem not from what **he or she** experiences, rather from the experiences his or her existence **makes possible for others**. He would argue that contribution could exist in the betterment of an individual and/or society, without the contributor's active initiation. Certainly, consideration of the circumstances of people with severe impairment benefits all human beings because all human beings stand at the threshold of impairment and might be moved into that realm by something as subtle as a bursting blood vessel or a texting driver. Being in relationship with a person with severe impairment, whether as an advocate, parent, family member, teacher, classmate, friend, or physician, can act as a catalyst for personal growth and fulfillment. Patience, perspective, tenacity, and appreciation of small achievements and just outcomes are qualities developed through experiences with disability.

¹⁶¹ Christopher D. Stone, *Should Trees Have Standing?: and other essays on law, morals, and the environment* (Dobbs Ferry, New York: Oceana Publications, 1996), 39.

Chapter Four

A Challenge to Rawls and an Introduction to the Capabilities Approach

*Correcting the oversight of previous theories is...not a matter of simply applying the same old theories to a new problem; it is a matter of getting the theoretical structure right.—Martha Nussbaum, *Frontiers of Justice**

Nussbaum and Amartya Sen critique social contract theory in general and justice as fairness specifically on many grounds, but for the purposes of this work, as exclusionary to people with severe impairment. They offer an alternative, and in some ways unrelated, model, which they refer to as the *capabilities approach*. Nussbaum, from a philosophical perspective and Sen, from one of comparative economics, individually and collaboratively develop a neo-Aristotelian definition of what it is to be human, an enumeration of what humans must be capable of to enjoy a minimum threshold of flourishing, and ideas on how these capabilities might be achieved through the marriage of the basic “innate equipment of individuals,” community participation in the development of that basic equipment, and social supports to fill in the gaps, missing for all people. Since capabilities theory sees humans as interdependent and unbound to a requirement of autonomy, those with severe cognitive impairment can fulfill many capabilities, as support from others can bridge gaps in natural endowments. The development of the capabilities approach attempts to remediate the deficits of social

contract theory, which Nussbaum believes developed as a result of the social sequestration of people with disabilities and their subsequent lack of inclusion in political theory.¹⁶²

Historically, during the chronological parameters of social contract theory development, people with severe physical and intellectual impairment were excluded from most community activity. In the wealthy classes, they were sequestered within family homes, but generally they lived within asylums and institutions, perhaps laboring in work houses, where adults with impairment produced products through menial, repetitive tasks for a pittance, and children languished with low expectations and insignificant education. This sequestration model persisted into the middle of the twentieth century, with remnants evident into the present day.

A lawsuit was filed in 2010 on behalf of an inmate at the Colorado State Penitentiary at Cañon City. Troy Anderson, a forty-year-old who has spent twenty-three of those years in prison, has been diagnosed since early childhood with a variety of mental health problems including Attention Deficit Hyperactivity Disorder, Bipolar Disorder, Intermittent Explosive Disorder, Antisocial Personality Disorder, cognitive disorder, and seizure disorder, all likely the result of an organic brain syndrome. Anderson has been held in administrative segregation, essentially solitary confinement, for ten years with only five hours a week for showers and recreation, which takes place within an indoor day hall, with no view of the outside and no access to the outdoors. He is allowed two books per year. Officials justify his sequestration on the basis of his

¹⁶² Martha C. Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership* (Cambridge, Massachusetts: The Belknap Press of the Harvard University Press, 2006), 15-16.

potentially dangerous behavior. Anderson has demonstrated improvement in his conditions when he takes prescribed psychiatric medications. Prison psychiatrists, the latest in a long line of mental health professionals, have prescribed these medications, but the prison system, in the persons of Warden Susan Jones and Aristedes Zavaris, Executive Director of the Colorado Department of Corrections, has refused to administer the medications prescribed by its own doctors. Without the medications, Anderson cannot control or improve his actions and so the withholding of treatment assures that he cannot demonstrate good behavior that would not only allow him to join the general prison population, but ultimately shorten his sentence. The law firm of Fox and Robertson, in conjunction with the University of Denver Civil Rights Clinic, has filed a complaint, citing violations of his Eighth (cruel and unusual punishment) and Fourteenth (due process and incorporation doctrine) Amendment rights.¹⁶³

In a different instance of sequestration, in 2008, Alex Barton, a kindergarten student with a suspected autism spectrum disorder was sent to the principal's office for a class disruption. According to his mother, when he returned to his classroom, his teacher, Wendy Portillo, forced Alex to stand in front of his fellow students while they enumerated what they did not like about him. The students were then asked to vote on whether Alex could stay in the class. Fourteen of the sixteen students voted to expel him.¹⁶⁴ Though these cases seem unrelated, both people with disabilities were unsupported in ways, which, if implemented, might have manifested in acceptable social

¹⁶³ *Anderson vs. Colorado*, U.S. District Court for the District of Colorado, Case # 1:10-cv-01005-RBJ-KMT

¹⁶⁴ Colleen Wixon, "Autistic Student, Mom Receive Worldwide Support," *TCPalm*, 29 May 2008, @<http://www.tcpalm.com/news/2008/may/29/30gt-autistic-student-mom-receive-worldwide-hed/>

interaction. Instead of providing Barton with testing, paraprofessional support, or an acceptable discipline plan—instead of providing Anderson with prescribed medications and therapy, these struggling individuals were shunned, separated, and punished.

Specifically in these cases and in the severely impaired population as a whole, physical and attitudinal barriers have discouraged community participation. Under these circumstances, per Nussbaum, it is no wonder that contract theorists in general fail to address exclusionary concepts like *rational choosers*, *rough equality*, *reciprocity* and *mutual advantage*. All traditional contract theories rely on the inherent rationality of participants, which allows for an understanding of the contract and the bargaining required in its development as well as an understanding of one's ends and the best means for their achievement. Yet, as Nussbaum points out:

A satisfactory account of human justice requires recognizing the equal citizenship of the mentally disabled... It also requires recognizing the many varieties of disability, need, and dependency that 'normal' human beings experience, and thus the very great continuity between 'normal' lives and those of people with lifelong mental disabilities.¹⁶⁵

According to Nussbaum, Rawls's specific use of a Kantian conception of persons as autonomous and rational precludes participation by people with severe cognitive impairment. Kant understands rationality, which allows moral judgment, to be the attribute, which separates man from animal and makes humans worthy of the considerations of justice. Nussbaum criticizes Rawls's endorsement of Kant as

¹⁶⁵ Martha C. Nussbaum, "Capabilities and Disabilities: Justice for Mentally Disabled Citizens," *Philosophical Topics* 30, no. 2 (Fall 2002): 135.

foundational to justice as fairness. In loading his theory in such a way, she believes it can never be inclusive. She discusses Kant's notion of a bifurcated citizenry:

Kant acknowledges that there will be citizens in the society who are not active contracting parties and who are not characterized by independence. ...All such people 'lack civil personality' because they are not independent. This thought leads Kant to distinguish between 'active' and 'passive' citizens. Active citizens (who I understand to be the group who are also framers of the social contract) have the right to vote on account of their independence... Members of the other group...have no right to vote, to hold political office, even 'to organize, and to work for the introduction of particular laws.'¹⁶⁶

The author would like to point out that Rawls incorporates the notion of active and passive citizens in a more nuanced way than does Kant. Nuanced in the sense that while there are individuals who meet the criteria for entitlement to equal justice and those who do not, just as in Kant's theory, instead of making judgments, as Kant does, about the irrational nature of whole groups of people (women, children, people with impairment), Rawls looks at the individual person's capacities.

Nussbaum asserts that Rawls's moral persons are:

...distinguished by two features: first they are capable of having (and are assumed to have) a conception of their good (as expressed by a rational plan of life); and second they are capable of having (and are assumed to acquire) a sense of justice, a normally effective desire to apply and to act upon the principles of justice, at least to a certain minimum degree.¹⁶⁷

Thus, those who occupy the least rational end of the rational to non-rational continuum fail to merit status for Rawls, and while he does not see this as a significant problem, it

¹⁶⁶ Martha C. Nussbaum, *Frontiers of Justice*, 52.

¹⁶⁷ John Rawls, *A Theory of Justice*, 442.

certainly prohibits justice as fairness from consideration as a universal theory of justice. But Rawls is not Kant and while his citizens must demonstrate a capacity for reasoning, his understanding of social unions does leave an opening for the expansion of qualifiers and the notion that a society benefits from diversity.

In singularly revering the skills made possible by the ability to reason while failing to recognize the importance of non-rational human capacities, Kant does leave people who lack rationality without both respect and a place as a contributor within social structures. Rawls, however, while not fully developing the concept, understands that the community is a force multiplier—richer, more textured, with greater understanding and grasp of the issues, greater in the tasks it can accomplish and the support it can give its members, greater even than the most endowed member within its ranks standing alone. He offers the best reason for living in community. Rawls says:

It is a feature of human sociability that we are by ourselves but parts of what we might be. We must look to others to attain the excellences that we must leave aside, or lack altogether. The collective activity of society, the many associations and the public life of the largest community that regulates them, sustains our efforts and elicits our contribution. Yet the good attained from the common culture far exceeds our work in the sense that we cease to be mere fragments: that part of ourselves that we directly realize is joined to a wider and just arrangement the aims of which we affirm.¹⁶⁸

In this important statement, Rawls reveals an Aristotelian position and the promise of inclusion for people with impairment if society can grasp the value of these individuals. The author will always acknowledge that the ability to see and solve

¹⁶⁸ John Rawls, *A Theory of Justice*, 464.

problems—to view a desired future and plot a course to its fulfillment is essential in designing and governing a society. But the author fails to understand why the rational designers cannot be joined in their efforts by others, who contribute understandings of human interdependency, the beauty of relationship, the benefits of diverse experience, and the vulnerability inherent in the human condition. The author wonders whether the rational human is better off hiding from the inevitability of the loss of physical and mental functioning—hiding from the fact that later today she might lose the ability to walk or even think clearly. Does the thinker really benefit from pretending he knows the future and the expectation that he will maintain health and corporeal perfection? The understandings of the designers, if informed by reality and the *acceptability* of that reality, will acknowledge human vulnerability and further develop supports that remove the fear, loneliness and uncertainty that accompany impairment if individuals are isolated and marginalized. Without the inclusion of people who demonstrate every variant of the human condition, designers cannot possibly envision and build a society imbued with the ability to anticipate what tomorrow will bring for everyone, even the leaders, innovators, and valedictorians. So, the inclusion of people with severe impairment becomes not only a moral imperative, but beneficial practice for even the most self-interested.

Nussbaum demonstrates her understanding of the holistic human as she critiques the Kantian perspective of a schism within human nature. Kant sees the rational and moral powers of a human being in conflict with his animal nature, which creates a constant tension. Nussbaum points out that while Rawls does not subscribe to this dualistic view, his acceptance of the Kantian “person,” whose rationality Kant views as the sole vehicle to freedom and autonomy, inevitably leads to an empirical “split between

our rational and moral powers and the other aspects of the human animal.”¹⁶⁹ Nussbaum points out that disrespecting the animal aspects of a human being forces us to wrongly see human dignity as similar to the dignity of God and angels (Kant’s other rational beings) instead of a unique, and rather heroic, dignity developed within the animalistic parameters of mortality and vulnerability.¹⁷⁰ She further says that the Kantian split “wrongly denies that animality can itself have a dignity; thus it leads us to slight aspects of our own lives that have worth and to distort our relation to the other animals.”¹⁷¹

Thirdly, Nussbaum points out that separating rationality from human animal nature

makes us think of the core of ourselves as self-sufficient, not in need of the gifts of fortune; in so thinking we greatly distort the nature of our own morality and rationality, which are thoroughly material and animal themselves; we learn to ignore the fact that disease, old age, and accident can impede the moral and rational functions, just as much as the other animal functions.¹⁷²

Finally, Nussbaum believes that perceiving humans as split entities encourages the erroneous notion that our “core” is outside of time. She says,

Thinking in this way, we may forget that the usual human life-cycle brings with it periods of extreme dependency, in which our functioning is very similar to that enjoyed by people with mental or physical disabilities throughout their lives.¹⁷³

¹⁶⁹ Martha C. Nussbaum, *Beyond the Social Contract: Toward Global Justice*, last modified 2003, http://www.tannerlectures.utah.edu/lectures/documents/volume 24/nussbaum_2003.pdf, 427.

¹⁷⁰ Martha C. Nussbaum, *Beyond the Social Contract*, 427.

¹⁷¹ Martha C. Nussbaum, *Beyond the Social Contract*, 427.

¹⁷² Martha C. Nussbaum, *Beyond the Social Contract*, 427-428.

¹⁷³ Martha C. Nussbaum, *Beyond the Social Contract*, 428.

Nussbaum believes that had Rawls completely rejected Kant's duality of the rational and the animal nature within humans, he would have more effectively approached an inclusive theory.¹⁷⁴ The author wishes to point out that Rawls does provide for the inclusion (based on rationality) of most people on the impairment spectrum in that he requires a minimum degree of rationality rather than Kantian "independence," while acknowledging that his Kantian foundation prevents a fully inclusive perspective.¹⁷⁵ He feels less ambivalent than Nussbaum, however, in his assertion that modifications to justice as fairness can occur without its loss of identity. For this to occur, more than just its Kantian essence must be modified, however.

Nussbaum observes that Rawls's adherence to Humean doctrines, which limit where justice can operate, necessitates his qualification that designers be "roughly equal." She notes that the contract tradition requires rough equality among participants in order to justify their equal treatment. She questions whether rough equality of "power and capacity" must necessarily be linked to *moral* equality. Nussbaum thinks these can be delinked so that regardless of unequal endowments, humans remain morally equivalent and hence equally deserving of moral recognition.¹⁷⁶ She points out that Rawls, in contrast to earlier contract theorists, "...distinguishes between these two types of equality" yet regrets that he continues to require both from his participants.¹⁷⁷

¹⁷⁴ Martha C. Nussbaum, *Frontiers of Justice*, 66.

¹⁷⁵ John Rawls, *Political Liberalism*, 183.

¹⁷⁶ Martha C. Nussbaum, *Frontiers of Justice*, 31.

¹⁷⁷ Martha C. Nussbaum, *Frontiers of Justice*, 31.

Nussbaum presents a powerful critique of Rawls, but can her desire for moral equivalency escape the broader rationality problem and the ways it affects social perceptions of value, which prohibit full inclusion. Nussbaum identifies with the liberal political tradition and considers the capabilities approach as “another member of this family” of “liberal conceptions.”¹⁷⁸ In *Sex and Social Justice*, she says:

At the heart of this tradition is a twofold intuition about human beings: namely, that all, just by being human, are of equal dignity and worth, no matter where they are situated in society, and that the primary source of this worth is *a power of moral choice within them, a power that consists in the ability to plan a life in accordance with one's own evaluation of ends* (italics the author's). To these two intuitions—which link liberalism at its core to the thought of the Greek and Roman Stoics—the liberal tradition adds one more, which the Stoics did not emphasize: That the moral equality of persons gives them a fair claim to certain types of treatment at the hands of society and politics. What this treatment is will be a subject of debate within the tradition, but the shared starting point is that this treatment must do two closely related things. It must respect and promote the liberty of choice, and it must respect and promote the equal worth of persons *as choosers* (italics the authors).¹⁷⁹

This language seems to the author to be ambiguous, simultaneously offering universality and tying moral equality to the ability to choose. Nussbaum bases her position on separating moral equivalency from equality of power on the works of Hugo Grotius. While this is her response to Hume and rough equality, it is unfortunate that Grotius, too, bases his notion of moral equivalency on human rationality.¹⁸⁰

¹⁷⁸ Martha C. Nussbaum, *Frontiers of Justice*, 6.

¹⁷⁹ Martha C. Nussbaum, *Sex and Social Justice*, (New York, New York: Oxford University Press, 2000), 57.

¹⁸⁰ Martha C. Nussbaum, *Frontiers of Justice*, 38.

In her later work on Rawls and impairment, *Frontiers of Justice: Disability, Nationality, Species Membership*, Nussbaum distances herself from her earlier statement. She says, "...any child of human parents has the fully equal dignity that belongs to every human being."¹⁸¹ The author assumes that this statement, with which he agrees, stems from her understanding that humans and relationship are deeply interwoven, instead of this being an argument based on DNA, yet if she criticizes Rawls for a reliance on Kant, she must be criticized equally for identification with the reason-centric Grotius. Either moral equivalency is based on a person's ability to choose and people without that ability are moral outliers, or another reason for moral equivalency must be articulated. Moral equivalency is the basis for personhood and with that status, an expectation that other persons are obligated to reciprocate agreed upon goods, among these, rights and supports toward the development of capabilities.

In *Women and Human Development*, Nussbaum describes her frustration with "the language of rights," stating that a lack of clarity obscures understanding. She states, "People differ about what the *basis* of a rights claim is: rationality, sentience, and mere life have all had their defenders."¹⁸² Instead of discussing claim rights, Nussbaum formulates a list of capabilities unique to her version of the theory, which need not be claimed by an offended individual, rather facilitated by the individual's government, community, family, allies, or the individual herself. These "functionings" include basic capabilities (things with which a person is born that provide functional abilities like

¹⁸¹ Martha C. Nussbaum, *Frontiers of Justice*, 38.

¹⁸² Martha C. Nussbaum, *Women and Human Development: The Capabilities Approach*, (Cambridge, United Kingdom: Cambridge University Press, 2000), 97.

hearing and sight), internal capabilities (things that a person is born with the potential for, but which must be developed like intellect and mobility), external capabilities (social, cultural, and political circumstances, which support human flourishing), and combined capabilities (successfully developed internal capabilities existing within an environment, which allows and encourages their expression).¹⁸³ Nussbaum's comprehensive list represents what is necessary for each human being to achieve a minimum threshold of flourishing. She sees the capabilities as achievable through a variety of supports, including statute, natural supports (such as help from family and friends), education toward the goal of developing just social norms, economic empowerment tools (such as microfinance), and political participation. She includes:

1. **Life.** Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.
2. **Bodily Health.** Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.
3. **Bodily Integrity.** Being able to move freely from place to place; having one's bodily boundaries treated as sovereign, i.e. being able to be secure against assault, including sexual assault, child sexual abuse, and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.
4. **Senses, Imagination, and Thought.** Being able to use the senses, to imagine, think, and reason—and to do these things in a 'truly human' way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing self-expressive works and events of one's own choice,

¹⁸³ Martha C. Nussbaum, *Women and Human Development*, 84-85.

religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to search for the ultimate meaning of life in one's own way. Being able to have pleasurable experiences, and to avoid non-necessary pain.

5. **Emotions.** Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by overwhelming fear and anxiety, or by traumatic events of abuse or neglect. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)

6. **Practical Reason.** Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience.)

7. **Affiliation.**

- A. Being able to live with and toward others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another and to have compassion for that situation; to have the capability for both justice and friendship. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.)
- B. Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails, at a minimum, protections against discrimination on the basis of race, sex, sexual orientation, religion, caste, ethnicity, or national origin. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.

8. **Other Species.** Being able to live with concern for and in relation to animals, plants, and the world of nature.

9. **Play.** Being able to laugh, to play, to enjoy recreational activities.

10. **Control over One's Environment.**

A. **Political.** Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association.

B. **Material.** Being able to hold property (both land and movable goods), not just formally but in terms of real opportunity; and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure.¹⁸⁴

The author assumes Nussbaum intends universal inclusion in the capabilities approach, since she critiques Rawls as exclusionary, yet he finds many of the capabilities unachievable for people with impairment. He will never have complete bodily health and may not realize a “normal” lifespan. People with sensory deficits will be challenged in ways that statute, natural supports, education, and political participation cannot mitigate. People with severe cognitive impairment will never reason or require liberty of conscience or freedom of expression. The author lauds Nussbaum's list, but imagines that the person with severe impairment was not the citizen she envisioned during its creation.

While most of us would prefer to live to a “normal” age, it is even more important to live each day with knowledge of the respect of our neighbors—to be understood to be valuable and contributory, no matter the form of the contribution. While each of us

¹⁸⁴ Martha C. Nussbaum, *Woman and Human Development*, 78-80.

would prefer not to cough or limp, to breathe independently instead of with artificial respiration, to live without surgeries and medication, what is more important is that our neighbors respect us despite the evidence of our imperfections and that professionals treat us like people first with preferences, points of view, and the need to control what is done to our bodies. All of these things are necessary to reach a status of “moral equivalency.” Nussbaum’s list is valid and comprehensive for a human being without impairment, but it neglects a primary good which must be delivered by a just society—that of acceptance through the acknowledgement of the equal potential value and contributory power held by all human beings. People might lose the respect of society through the performance of intentional anti-social acts, but no one should live without respect from the moment of their birth or throughout a blameless life.

Sen offers a list of less detailed, but equally complex (in terms of implementation) capabilities. He includes “*economic opportunities, political freedoms, social facilities, transparency guarantees, and protective security.*”¹⁸⁵ Ingrid Robeyns, professor in Practical Philosophy at Erasmus University, critiques Sen in particular and the capabilities approach in general as being impossible to implement. Referencing Robert Sugden, she says:

...given the rich array of functionings that Sen takes to be relevant, given the extent of disagreement among reasonable people about the nature of the good life, and given the unresolved problem of how to value sets, it is natural to ask how far Sen’s framework is operational. Is it a realistic alternative to the methods on which economists typically rely—measurement of real income, and the kind

¹⁸⁵ Amartya Sen, *Development as Freedom* (New York, New York: Anchor Books, a division of Random House, 1999), xii.

of practical cost-benefit analysis which is grounded in Marshallian consumer theory?¹⁸⁶

She continues:

The capability approach in practice comes in a variety of forms, in part because of the wide scope of the approach, but also because the approach is radically *underspecified*: there are a number of theoretical lacunae that can be filled in a variety of ways. How one makes these specifications depends in part on the kind of theory (for example, a theory of justice, or a theory of welfare economics) or the kind of application (for example, a critique on existing social practices, or a measurement exercise), but it also depends in part on particular normative and epistemological assumptions.¹⁸⁷

The capabilities approach and, incidentally, resourcist approaches, as well, could equally depend on normative assumptions that are either emancipatory or stifling. Only the original position assures that they be freedom-and-justice-enhancing. Furthermore, nowhere in Nussbaum or Sen's offerings is the intrinsic contribution and value of people with severe impairment addressed. Nussbaum talks about justice towards this population being a good in and of itself, but does not talk about any intrinsic value within the person with impairment.

In order to fully gain value, such that a new mother of a baby with impairment no longer mourns the birth of her baby, such that a young man after acquiring a spinal cord injury no longer contemplates suicide, such that an old woman who needs help to toilet no longer writes a letter to the Hemlock Society, and such that a doctor no longer fails to treat a curable disease in a intellectually impaired man, it is the duty of the theorist to

¹⁸⁶ Ingrid Robeyns, "The Capability Approach in Practice," *The Journal of Political Philosophy* 14, no. 3 (2006): 352.

¹⁸⁷ Ingrid Robeyns, "The Capability Approach": 353.

make a convincing argument for the actual—not euphemistic—contribution made by people with severe impairment. Despite her call for moral equivalency, Nussbaum does not venture into this realm. Her demand that humans have “the social bases of self-respect and non-humiliation” which includes being “treated as a dignified being whose worth is equal to that of others” assigns rather than observes value.

The author, even as he argues for the inclusion of non-rational acts of contribution within the rubric of reciprocity, acknowledges that relational acts and catalytic circumstances, either produced or encouraged by people with severe cognitive impairment, cannot, on their own, maintain the institutions of justice, democracy, philosophy, or politics. He does argue and believe that alongside traditional duties, extra-rational contribution benefits humankind and must be acknowledged for its additional value. He thinks that justice as fairness can absorb this perspective and maintain its identity.

But, as it stands, people with severe impairment are understood to be excluded from justice as fairness not only because of the rationality problem, but also because they cannot meet the test of rough equality. Nussbaum notes that Rawls must incorporate the Humean concept of “rough equals” to deal with the contract problem of bargaining. If extraordinarily vulnerable people find themselves in the bargaining position, they are apt to be coerced into positions of further disadvantage, even perhaps slavery.¹⁸⁸ This is especially true of people with severe cognitive impairment. Even if they could form some concept of their ends, they would be disadvantaged in a situation of competitive

¹⁸⁸ Martha C. Nussbaum, *Frontiers of Justice*, 28, 29.

bargaining by a lack of understanding as to how differing means might, or might not, lead to their chosen ends. But, is traditional bargaining essential to justice as fairness?

Norman Daniels, Mary B. Saltonstall Professor of Population Ethics at Harvard University, takes issue with the idea that once in the original position, bargaining in any competitive sense would take place. If this is true, references to whether or not people have the capability of successfully bargaining are moot. He says:

Rawls rejects the idea that the contract involves bargaining. Instead, moral claims about the fundamental equality of citizens, as well as their freedom, shape the design of his contract situation. He places contractors behind a veil of ignorance that blinds them to the specifics of their own situation. The result is that contractors must be impartial and cannot help but avoid judgments that might be biased in favor of people with their actual talents, skills, capabilities, or needs. So forceful is the restriction on knowledge of differences that any sense of bargaining away disagreements is eliminated...It would clearly be unfair criticism to lump Rawls with those squarely in the bargaining tradition.¹⁸⁹

The issue of rationality needed for bargaining aside, Rawls hints that people with unusually extreme support needs, even those with the ability to reason, might be too expensive to be welcome at the bargaining table; thus people, like the author, who have need of a much higher than typical consumption of goods, despite the presence of arguable rationality, might be too far from being “rough equals” in terms of goods consumption to qualify under a system of mutual advantage. Since, for Rawls, the circumstances of justice mimic the state of nature, “undesirables” would be prevented

¹⁸⁹ Norman Daniels, “Justice and Long Term Care: Need We Abandon Social Contract Theory? A Reply to Nussbaum,” in *Ethical Choices in Long-Term Care: What Does Justice Require?*, ed. Oni Annette LaGioia (Geneva, Switzerland: World Health Organization, 2002), 68.

from entering the original position. Specific information about what constitutes undesirability is elusive. In responding to Sen and Kenneth Arrow's observations about human variation, including impairment, Rawls says,

...Let us...ask whether a variation places people above or below the line: that is whether it leaves them with more or less than the minimum essential capacities required to be a normal cooperating member of society."¹⁹⁰

One of the variations Rawls discusses is "a variation in physical capacities and skills, including the effects of illness and accident on natural abilities." Would Rawls agree with an interpretation that one's extraordinary degree of need for economic goods, as in the case of people with severe physical impairment, would be a consideration in whether one could participate? Nussbaum is sure of Rawls's position. She says:

...the idea is that people will get together with others and contract for principles of justice only in certain circumstances in which they can expect mutual benefit and in which all stand to gain from the cooperation. To include in the initial situation people who are unusually expensive, or who can be expected to contribute less than others to the well-being of the group, would go contrary to the logic of the whole exercise. If people are making a bargain for mutual advantage, they will want to get together with those from cooperation with whom they expect to gain, not those who will demand unusual and expensive attention without contributing anything much to the social product, thus depressing the level of society's well-being.¹⁹¹

Nussbaum is correct that Rawls (and not just the more egoistic contract theorists like David Gauthier whom she later quotes) acknowledges and entertains the economic

¹⁹⁰ John Rawls, *Political Liberalism*, 183.

¹⁹¹ Martha C. Nussbaum, *Beyond the Social Contract*, 424.

reasoning behind deferring decisions about the economic needs of people with extraordinary circumstances. Rawls states:

...the variations that put some citizens below the line as a result of illness and accident (once we allow for these) can be dealt with, I believe, at the legislative stage when the prevalence and kinds of these misfortunes are known and the costs of treating them can be ascertained and balanced along with total government expenditure.¹⁹²

While Sen comments on Rawls's "pervasive sympathy for the disadvantaged" including his recommendation for "special correctives" for people with impairment, he questions whether justice can be achieved in light of their postponement. He says:

These corrections come not in setting up 'the basic institutional structure' of the society at the 'constitutional stage', but as something that should emerge later on in the *use* of the institutions thus set up, particularly in the 'legislative stage'. This makes the reach of Rawls's motivation clear enough, and the question to be asked is whether this is adequate as a way of rectifying the partial blindness of the perspective of resources and primary goods in Rawlsian principles of justice.¹⁹³

Sen continues in pointing out the most important problem inherent in postponement to the legislative phase—the fact that the basic institutions set up in the original position are “not at all influenced” by the special issues of those with impairment.¹⁹⁴ The author has to acknowledge that in deferring justice for people with extraordinary economic needs to a legislative phase, Rawls does deny the person, whose existence requires extreme societal economic support, participation in the original position and whatever corrections

¹⁹² John Rawls, *Political Liberalism*, 184. When Rawls describes the “line” he is referring to that which delineates participants from non-participants in the Original position.

¹⁹³ Amartya Sen, *The Idea of Justice* (Cambridge, Massachusetts: The Belknap Press of Harvard University Press, 2009), 260-261.

¹⁹⁴ Amartya Sen, *The Idea of Justice*, 261.

are made at the legislative phase will only be patches on a basically flawed fundamental structure. This brings to the author's mind the image of retrofitting a structure to comply with the ADA instead of designing the building, from its inception, with all possible users in mind.

Nussbaum assumes that people in the original position would know that they are not severely impaired and hence not veiled from that possibility for two reasons. First, they would know because Rawls's endorsement of Hume's "circumstances of justice," which require rough equality among contractors would prevent the participation of all severely impaired individuals, and second because the pool of desirable partners in the contract would not include the burdensome. Thus, in Nussbaum's interpretation, no one with severe impairment would be allowed to participate, and so would never be found under the veil.

She is frustrated with Rawls's reticence to allow participation by all those with physical impairment. She says, "So: let the parties in the Original Position not know what physical disability they may or may not have. Then, and only then, will the resulting principles will (sic) be truly fair to people with disabilities."¹⁹⁵

Nussbaum finds three reasons for Rawls's inability to make this adjustment. One argument for why Rawls is unable to accept people with extraordinary physical needs under the veil is related to the intersection of statistical knowledge allowed in the original position and the assumed assertion of mutual advantage, in the traditional sense of that term, as discussed above. She correctly states that people in the original position have

¹⁹⁵ Martha C. Nussbaum, *Beyond the Social Contract*, 432.

basic knowledge of the world, including statistics about the prevalence of types of impairment. She worries that since they would know that only a small percentage of humans have particular impairments, the rarity of which require extraordinary economic mitigation, they would be unwilling to expend community resources on beings so expensive and with such little likelihood of economic reciprocation.¹⁹⁶

Nussbaum further explains that society's public spaces are designed with statistical probabilities surrounding impairment in mind. She describes "normal" impairments, which are addressed regularly in community design. Mitigation of limitations that are ordinary is widely accepted. No one expects a human being to levitate ten feet to enter an elevated building. But because that mitigation is based on statistical probabilities, stairs are built, which cater to how the vast majority of people rise to higher ground. The height of a step is designed with a typical gait in mind. A handrail is added only if a typical person would need one for safety. An elevator replaces stairs only if a typical person would become winded in a circumstance of having to climb many stairs. The typical American, having lived with the Americans with Disabilities Act for many years might find this argument antiquated, but on an international scale, it makes sense.

Her point finally comes down to economics. She states:

The real issue for the contractarian, however, is the relative rarity of the non-'normal' impairments (defined as not 'normal' just by reference to their relative rarity); this rarity entails that expensive and difficult arrangements will have to be made to make work and public space fully accessible

¹⁹⁶ Martha C. Nussbaum, *Beyond the Social Contract*, 433.

to people who have them, enabling them to be ‘normally’
productive.¹⁹⁷

Nussbaum’s argument only holds when people with extraordinary impairment are denied access to the original position, for surely, if the possibility for impairment exists in the minds of the participants, infrastructure would be of universal design. Cost would be a factor only in the re-design of current structures. Nussbaum’s descriptions of the costs of restructuring public spaces for individuals with impairment are based on present reality, which the author thinks originally developed less from an expense perspective and more from the fact that people with impairment have been socially isolated for so long that their needs were, in the past when public spaces were designed, not considered at all. In any original design choices, if participants, whether people with impairment or people who might become impaired in the future, or people prescient enough to imagine that their children or grandchildren might have impairment, have a choice between stairs and a ramp, which cost about the same to create in the original installation, or between two typical bathroom stalls or one wide stall, which have similar bottom lines, or between a sloping shower floor that allows water to run to the drain or a shower stall with walls that contain the water, which have no significant cost differential, why wouldn’t they choose the more universal design? It is only in retrofitting the public spaces of the past, designed for a populace less heterogeneous than today’s that expense becomes a problem. So, this concern of Nussbaum’s is moot in incipient circumstances and only possibly valid in circumstances where the original position is to be used as an ongoing perspective. Even in the latter case, it would be valid only if participants are screened for

¹⁹⁷ Martha C. Nussbaum, *Frontiers of Justice*, 117.

ultimate goods consumption at the door and hence excluded from the original position or if included participants are risk takers to the degree that they are willing to risk the access of their future selves and those of their children and grandchildren.

In any configuration of participants in the original position, all would be veiled from their own circumstances. If, under these conditions, they are given statistical information that leads them to conclude that they are extremely unlikely to be severely impaired and if that influences them to take a risk and come to a consensus on the parameters of goods distribution, which leads to an unjust result, then justice as fairness would have failed and it would be revealed that if it is a system of pure procedural justice, which guarantees a just outcome if the system is loaded fairly, then the basic assumptions need to be reconsidered. The inclusion of statistical information about the prevalence of any expensive conditions that result in increased poverty would not load the system fairly if it is acknowledged that people might be willing to accept a risk if it is small and that people are driven to participate initially only if the system is guaranteed to be economically mutually advantageous, but the remedy seems simple. The exclusion of statistical information in the original position eliminates the contaminating aspect of the loading process. So, the author would argue that statistical information about the prevalence of severe impairment, which might encourage gambling on whether one might or might not be affected, must not be available under the veil.

Still, the author is not willing to assume that mutual advantage can only be described in economic terms. As the author has discussed, many forms of contribution exist beyond those based on economic reciprocity. While Nussbaum seems to acknowledge extra-rational contribution to some extent, she still sees relationships

between people lacking impairment and people with severe impairment to be “asymmetrical.” Because she doesn’t completely share the author’s position that non-rational people make extraordinary contributions, she cannot see any common ground between social contract theory and the inclusion of people with severe impairment.¹⁹⁸ If, on the other hand, value is observed and acknowledged, there is no incompatibility with mutual advantage arguments. The author contends that leaving people with severe impairment out of the recipe results in a much less rich, flavorful, and nuanced social cake. Nussbaum sees only a less *just* cake. She sees inclusion as a valuable moral good in and of itself, separate from any social benefit of reciprocal exchange. She says:

...why can’t Rawls simply adopt a more moralized conception of the benefits of social cooperation, one that includes the goods of inclusion, respect for human dignity, and justice itself as among the benefits the parties are seeking out of their social cooperation?...We choose to respect and include the disabled because it is good in itself to do so, whether it is economically efficient or not. Benefit should not be understood in purely economic terms, for there is the great good of justice itself to be considered. This reply is clearly in tune with one deep strand in Rawls’s thinking, and it is the sort of reply he makes often when he is talking about the idea of overlapping consensus and why the agreement of citizens in a well-ordered society is no mere *modus vivendi*.¹⁹⁹

So, Nussbaum acknowledges Rawls’s interest in the “great good of justice itself,” and the author is in complete agreement. But, Rawls also speaks to the good of social unions. The author contends that the more homogenous a society, the more “special cases,” outliers, and challenges are banished, the more the person next to you reflects your own image,

¹⁹⁸ Martha C. Nussbaum, “Capabilities and Disabilities,” 137.

¹⁹⁹ Martha C. Nussbaum, “Capabilities and Disabilities,” 147.

the less benefit will be realized from Rawls's social unions. Only diversity of viewpoint and experience will manifest in enrichment. This perspective does not seem to be so removed from Rawls's intention and is missed by Nussbaum.

Nussbaum's second line of reasoning, as to why Rawls cannot accept people with extraordinary needs in the original position, stems from her assertion that because justice as fairness evolves from the contract tradition, it cannot free itself from traditional contractarian notions of mutual advantage. Nussbaum quotes Gauthier,

The primary problem is care of the handicapped. Speaking euphemistically of enabling them to live productive lives, when the services required exceed any possible products, conceals an issue which, understandably, no one wants to face."²⁰⁰

He continues, "Such persons are not party to the moral relationships grounded by a contractarian theory."²⁰¹ So, now the addition of expensive people to the already exiled non-rational population is clearly observed. Rawls did state, in the previously quoted statement that care of the impaired would be deferred to a later, legislative stage. Gauthier takes a much more completely exclusionary position. Nussbaum's inclusion of such an ugly statement in her critique of Rawls is unfair and does not capture the spirit of his intent.

In her final explanation of why Rawls cannot include people with severe impairment in the original position, she cites his desire to have a simple economic measuring stick for determining who is the least advantaged for the purpose of

²⁰⁰ David P. Gauthier, *Morals by Agreement* (New York, New York: Oxford University Press, 1986), 18, no. 30.

²⁰¹ David P. Gauthier, *Morals by Agreement*, 18.

distributing goods per the difference principle. To prioritize “thing-like items, above all wealth and income” is to simplify the task.²⁰² Complicating the process with having to measure non-quantifiable goods such as physical abilities seems to Nussbaum to muddy the waters.²⁰³ She does acknowledge that Rawls identifies self-respect as “the most important” of the primary goods and thus has moved in the direction of complex (possibly the most complex) goods. She does not then proceed from that admission to suppose that extra-economic goods might find a place within justice as fairness, stating instead that if Rawls were to embrace a complex and heterogeneous definition of goods he would face two problems. She enumerates,

...first, how to balance one such good against another without giving way to ‘intuitionistic’ tradeoffs...second, how to think about social productivity in new multivalued terms, something that would cause a profound alteration in the whole logic of his contractarianism.²⁰⁴

Sen, for his part, criticizes Rawls’s focus on economic primary goods for its failure to assure that equality of well-being follows from the egalitarian distribution of these goods. Sen says:

...in the difference principle, Rawls judges the opportunities that people have through the means they possess, without taking into account the wide variations they have in being able to *convert* primary goods into good living. For example, a disabled person can do far less with the same level of income and other primary goods than can an able-bodied human being.²⁰⁵

²⁰² Martha C. Nussbaum, *Women and Human Development*, 66.

²⁰³ Martha C. Nussbaum, *Beyond the Social Contract*, 432-433.

²⁰⁴ Martha C. Nussbaum, *Beyond the Social Contract*, 433.

²⁰⁵ Amartya Sen, *The Idea of Justice* (Cambridge, Massachusetts: The Belknap Press of Harvard University Press, 2009), 65-66.

He continues:

If people were basically very similar, then an index of primary goods might be quite a good way of judging advantage. But, in fact, people seem to have very different needs varying with health, longevity, climatic conditions, location, work conditions, temperament, and even body size (affecting food and clothing requirements). So what is involved is not merely ignoring a few hard cases, but overlooking very widespread and real differences. Judging advantage purely in terms of primary goods leads to a partially blind morality...Indeed, it can be argued that there is, in fact, an element of 'fetishism' in the Rawlsian framework. Rawls takes primary goods as the embodiment of advantage, rather than taking advantage to be a *relationship* between persons and goods.²⁰⁶

Sen references a study by Robert Fogel and Stanley Engerman which finds that slaves in the pre-Civil War United States enjoyed economic well-being comparable to free agricultural laborers of the time. Nonetheless, they pursued the opportunity to escape bondage when possible. The impetus to freedom was separate from and greater than the economic status attached to it.²⁰⁷

Nussbaum might say that, in this example, dignity is defined by the achievement of freedom and that, if economic goods fail to deliver freedom, they fail, as well, to deliver dignity. The author understands that Nussbaum draws an important distinction between justice as fairness and the capabilities approach around the etiology of dignity. While Rawls's participants are understood to derive their dignity from their Kantian nature—in that they are reasonable and rational, Nussbaum's participants derive their

²⁰⁶ Amartya Sen, *Equality of What?: The Tanner Lectures on Human Values*, Delivered at Stanford University May 22, 1979, <http://www.tannerlectures.utah.edu/lectures/documents/sen80.pdf>, 215-216.

²⁰⁷ Amartya Sen, *Development as Freedom*, 28.

dignity from their achievement of the capabilities. These can be facilitated in many diverse ways, but do not necessarily rely on the individual autonomous person's inherent characteristics. Since the capabilities can be facilitated by others, people who lack rationality may achieve dignity through assistance.²⁰⁸

Nussbaum and Sen, believing Rawls's distribution of economic goods to fall short of assuring the complex array of needs-fulfillment essential to human flourishing, instead choose to determine final goals and then work backward to find both economic and non-economic means to those ends. Sen says,

The motivation behind Rawlsian reasoning, in particular his emphasis on advancing human freedom, is quite compatible with—and may be better served by—a direct concentration on the assessment of freedom, rather than counting the means towards achieving it.²⁰⁹

The capabilities approach is wedded to a way of looking at human need that goes beyond resources to visualize ways humans utilize resources. One way of looking at capabilities is to use the metaphor of eating food for nutrition. A typical person can eat a variety of wholesome foods and be nourished while a person with an enzyme deficiency or a metabolic insufficiency can eat the same diet and be malnourished. In the same way, one person might be able to flourish with basic economic goods, if other components of the capabilities are provided in her political, cultural, and social environment, while another person lacking an environment which nurtures and develops gifts, which is neither culturally egalitarian nor politically supportive, might receive the same, or even more abundant basic economic goods and fail to flourish.

²⁰⁸ Martha C. Nussbaum, *Frontiers of Justice*, 161-162.

²⁰⁹ Amartya Sen, *The Idea of Justice*, 234.

The author understands that not all goods needed to secure human flourishing are fundable and that it is indeed important to consider the part human relationship plays in the achievement of capabilities necessary to achieve this status. Nonetheless he finds Nussbaum and Sen's criticism of Rawls's econocentrism unnecessarily harsh. First, if it is assumed that all participants are original designers, then impediments to freedom, such as slavery, misogyny, or segregation, which Sen and Nussbaum consider outside of economic mitigation, would not be built into the norms formulated in the original position in the first place.

Second, because many impediments to full flourishing seen within the disability community can be successfully mitigated economically and when goods such as consumer directed care can be purchased, distribution of economic goods leads to dignity and self-respect. If an unorthodox understanding of the difference principle is embraced, and the uneven distribution of economic goods is allowed, such that people with impairment might receive a disproportionately large share, this might lead to a maximization of opportunity and increased justice might be possible within a Rawlsian economic framework. The author thinks it is reasonable to view the principle of equal liberty as mandating this unequal distribution of goods, if that is necessary for the achievement of equal levels of functioning. Money can be viewed as *potential energy*, capable of becoming a myriad of needed goods. As long as people with impairment (or their allies) are allowed control over the expenditure of the money, self-respect can be a foreseeable outcome.

While it is true that all aspects of well-being cannot be measured and compared, many needs can be calculated in terms of what it takes economically to maximize

opportunity. Even in cases of intellectual impairment, where it is acknowledged that the ability to reason cannot be purchased, the disproportionate distribution of economic goods toward the end of maximizing the benefits of excellent care giving, self-determination focused education, augmentative communication and other technologies that mitigate deficits, and support for community living all have an economic component. Discrepancies in fortune would have economic consequences due to Rawls's allowance that "the distribution of wealth and income" will be "determined by the natural distribution of abilities and talents."²¹⁰ So, when Rawls focuses on the distribution of economic goods alone it is because so many non-economic goods ultimately can be accessed through the proper expenditure of money and because many non-economic goods would be addressed in the original position. These would be inclusive of social attitudes. Thomas Pogge, Leitner Professor of Philosophy and International Affairs at Yale says of Rawls:

He...emphasizes the political liberties and their fair value as a crucial primary good that allows citizens, together, to shape the social and natural conditions that shape their lives. In these ways, a sophisticated resourcist view does take account of social conditions and of their potentially differential impact on persons and groups...²¹¹

Here Pogge defends Rawls's attention to needs, which cannot be addressed in an economic fashion. Here he speaks to the power of the original position.

If a priority-based conception of justice is to be maintained, however, the problem remains of determining economic distribution based on a measurement of who is the least

²¹⁰ John Rawls, *A Theory of Justice*, 64.

²¹¹ Thomas Pogge, "Can the Capability Approach be Justified?" *Philosophical Topics* 30, no. 2 (Fall 2002): 181.

well off. In a model that only considers rough equals, disparities would be minimal, but once people with impairment are considered, disparities move beyond the realm of income inequalities into another more challenging comparative realm. This new problem might be addressed by introducing a hybrid conception of justice, which maintains the difference principle and prioritizes the distribution of goods to the least advantaged while determining who is the least advantaged by measuring the amount of primary goods necessary to reach a sufficient level of capability. An examination of one's "functioning" or need and its ability to be addressed through the distribution of economic goods may be seen as the social support for individual development featured in Nussbaum's model. Rawls states that competition for careers must be open to talents and abilities without regard for social or economic standing. Nussbaum understands that the talents and abilities of which Rawls speaks often require external supports to fully manifest. Thus, for example, before "careers open to talents and abilities" can be competed for fairly, there must be development of innate equipment. Since it seems impossible to determine what a full development of a person's innate talents and abilities might be, it becomes necessary to draw a line at a *sufficient* level of development.

Sen discusses the meaning of a sufficient level of development:

Equality between persons can be defined either in terms of *attainments*, or in terms of the *shortfalls* from the maximal values that each can respectively attain. For 'attainment equality' of achievements, we compare the actual levels of achievement. For 'shortfall equality', what are compared are the shortfalls of actual achievements from the respective maximal achievements... Shortfall equality takes us in the direction of equal use of the *respective potentials*, whereas attainment equality is concerned with equal absolute levels of achievement (no matter what the maximal achievements are).

If human diversity is so powerful that it makes it impossible to equalize what is *potentially* achievable, then there is a basic ambiguity in assessing achievement, and in judging equality of achievement or of the freedom to achieve. If the maximal achievement that person 1 can have—under the most favourable circumstances—is, say, X, while person 2 can maximally manage 2X, then equality of *attainment* would leave person 2 invariably below his or her potential achievement...

In the case of serious disabilities, attainment equality may be hard to achieve, and it may be particularly tempting to opt for shortfall equality. There might well be a good argument in that direction, but I would like to argue that it is not the case that the choice is made clear-cut simply by the non-feasibility of attainment equality. It can be argued that even when a disabled person cannot, in any way, be given the freedom to enjoy the *same* level of the functioning in question,...there is nevertheless a good case—based on fairness—for trying to *maximize* his below-par functioning ability, rather than settling for the same shortfall (absolute or proportionate) as others have from their—much higher—maximal functioning.²¹²

Aside from the fairness argument, maximizing function for people with impairment might have the social benefit of reducing the costs of their supports. A sufficient level of functioning might be defined as the level attained when society has provided the resources to maximize function and a plateau has been reached over the course of a significant period of time.

This approach to development rarely happens in the case of people with severe impairment, as assumptions of inability and the corresponding belief that spending money toward this end is futile, override even *minimal* development of natural capacities. What it takes to support development toward the end of maximizing self-determination

²¹² Amartya Sen, *Inequality Reexamined*, (Cambridge, Massachusetts: Harvard University Press, 1992), 90-91.

must be assured and, for the purposes of resource allocation, can be translated into an economic rubric. For example, if a child with impairment requires a classroom aide to benefit from her education, then the salary of that aide can become part of the unequal distribution of economic goods. If she requires someone to sign for her, a communication device, an electronic tablet with appropriate applications, a physical educator trained in integrative strategies, or occupational therapy, these, too, can be provided for economically. As Rawls states, "...at the basis of the parties' reliance on primary goods is their recognition that these goods are essential all-purpose means to realize the higher-order interests..."²¹³ Other needs like appropriate teacher expectations, peer respect, and acceptance of unequal distribution of economic goods would be addressed in the original position through the choosing of the principle of equal liberty, if people with impairment are included participants. Thus, a certain blending of justice as fairness with a capabilities approach might prove helpful. Other contract theorists have appreciated the broader perspective offered by capabilities and have looked at their incorporation into justice as fairness.

Henry Richardson, student of Rawls and professor of philosophy at Georgetown University, offers an expansion of Rawlsian theory, which acknowledges Nussbaum's contribution and incorporates the notion of capabilities into justice as fairness. He begins by acknowledging Nussbaum's criticism of Rawls's postponement of justice for those beyond the typical range of capacity. Among the general reasons against postponement that Nussbaum adduces are the following:

²¹³ John Rawls, *Political Liberalism*, 76.

1. The pervasiveness of dependence and disability: Each of us enters life as a dependent infant lacking the capabilities of a fully cooperating member of society, almost all of us get seriously ill at some point, and many of us will be infirm and dependent again in old age.
2. The universality of care: Correspondingly, care-giving work by parents (most often mothers), doctors and nurses, and by one's children or the state is an essential feature of human life.
3. The continuum of disability: Each of us has capabilities that are defective in one way or another. There is a continuum (although not a clearly ordered one) in this regard.
4. The moral imperative to avoid drawing a dichotomy between the disabled and the non-disabled: Given the appalling history of social treatment of those with serious disabilities, it would be wrong to approach these issues with an 'us' and 'them' mentality.²¹⁴

Richardson also is wedded to the notion of the original position and the veil of ignorance.

He says:

Rawls's OP powerfully unites some fundamental convictions we have about morality, justice, and the appropriate constraints on developing principles. Its veil of ignorance represents a vivid way of combining common-sense thoughts about being in someone else's shoes with a kind of impartiality that neutralizes arbitrary inequalities of advantage. Its combination of the veil with the mutually-disinterested rationality of the parties aims to express something of the spirit of universal benevolence, but with more definite results. Because it captures ideals of empathy, impartiality, equality, rationality, and benevolence in these ways the OP represents a morally compelling viewpoint for us to consider as we begin to tackle the challenging issue of justice regarding disability.²¹⁵

²¹⁴ Henry S. Richardson, "Rawlsian Social-Contract Theory and the Severely Disabled," *The Journal of Ethics* 10 (2006): 421.

²¹⁵ Henry S. Richardson, "Rawlsian Social-Contract Theory": 424.

In order to address issues of impairment without postponement to a legislative stage, people with severe impairment must be represented in the original position. People in the original position are trustees for every conceivable individual in society.

Richardson states this in agreement with Rawls.²¹⁶ In addition to the ten stipulations placed upon the original position by Rawls, Richardson adds three more.²¹⁷ First, he insists on the “inclusion of all those with disability.” He states,

The parties are to assume that the persons they represent include persons of all levels of ability and disability, in such proportions as general knowledge about humans and human society would indicate.

This “implies that each of the parties is ignorant about the level of disability of the person on whose behalf it is to choose” and recognizes the above mentioned reasons for addressing impairment in the original position. Second, the parties in the original position must be given “the fundamental facts regarding disability” including

...that disability is a pervasive and unavoidable feature of human life..., that care-giving work is an essential feature of human life... and that all humans have capabilities that are defective in some regard, there being a continuum of disability.

²¹⁶ Henry S. Richardson, “Rawlsian Social-Contract Theory”: 440-441.

²¹⁷ Rawls’s ten general features of the Initial Choice Situation (ICS) per Richardson include: 1. Each ICS is to be viewed as a hypothetical perspective. 2. Characteristics of participants in the ICS are stipulated. 3. The parties are presented with a finite list of possible sets of principles from which to choose. 4. The parties are to choose principles intended to govern the basic structure of society. 5. In comparing principles, the parties must consider anticipated ends in a well-ordered society in which those principles form the basis of a publicly accepted conception of justice. 6. Participants are veiled from the characteristics of those they represent and of their society. 7. The participants are to expect that principles they choose will be implemented via constitutional and legislative provisions. 8. The parties are trustees on behalf of unknown persons. 9. Each party cares only about and promotes the goods beneficial to the persons represented under conditions of mutual disinterest. 10. The parties are to assume that society is characterized by moderate scarcity, a variety of religious and ethical conceptions from which to choose, and mutual advantage. From Henry S. Richardson, “Rawlsian Social-Contract Theory”: 439-441.

Finally, individuals in the original position must accept “that it would be wrong for principles of basic justice to invoke a simple dichotomy between ‘the disabled’ and ‘the non-disabled.’”²¹⁸ Richardson in no way suggests that non-reasoners will be among the choosers in the original position, only that they will be represented. He says, “...the parties choose as trustees on behalf of the ‘unknown’ persons they represent...The severely mentally disabled of course cannot reason about principles of justice...”²¹⁹ Thus, when Richardson speaks of “inclusion” he means inclusion as representee, not representor.

Richardson wonders what principles of justice might develop in the original position if people with severe impairment were represented. He begins by offering Rawls’s principles of justice from *Political Liberalism*:

1. Each person has an equal claim to a fully adequate scheme of equal basic rights and liberties, which scheme is compatible with the same scheme for all; and in this scheme the equal political liberties, and only those liberties, are to be guaranteed their fair value [the ‘First Principle’].
2. Social and economic inequalities are to satisfy two conditions:
 - A. first, they are to be attached to positions and offices open to all under conditions of fair equality of opportunity [the ‘equal opportunity’ principle]; and
 - B. second, they are to be to the greatest benefit of the least advantaged members of society [the ‘difference principle’].²²⁰

²¹⁸ Henry S. Richardson, “Rawlsian Social-Contract Theory”: 442-443.

²¹⁹ Henry S. Richardson, “Rawlsian Social-Contract Theory”: 440-441.

²²⁰ Henry S. Richardson, “Rawlsian Social-Contract Theory”: 435.

Richardson calls attention to a statement made by Rawls, which argues for Rawls's acceptance of an additional, lexically prior principle, which might be added before the above stated principles of justice. Rawls states:

...important aspects of the principles are left out in the brief statement as given. In particular the first principle covering the equal basic rights and liberties may easily be preceded by a lexically prior principle requiring that citizens' basic needs be met, at least insofar as their being met is necessary for citizens to understand and to be able fruitfully to exercise those rights and liberties. Certainly any such principle must be assumed in applying the first principle.²²¹

According to Richardson, people in the initial choice situation would have four possible choices when developing principles of justice. He suggests that parties who conceive of the good in terms of "rights, liberties, opportunities, income, wealth, and the social basis of self-respect, understood as the self-respect of the equal citizen" would choose the original Rawlsian principles, without modification as above.

Parties who understand the good as an amalgam characterized by "rights, liberties, opportunities, income, wealth; by fundamental self-respect; and by the capabilities" would choose, as a lexically prior principle, in addition to Rawls's two principles of justice, a Nussbaum-influenced, Richardson-revised option, which addresses human needs in terms of capabilities. It states, "The basic institutions of society are to be arranged so as to assure, so far as reasonably possible, that each citizen reaches a threshold level of capability in each of the ten basic types of human capability."

People who consider the capabilities approach as the best vehicle for the satisfaction of human needs would choose Richardson's procedural construction of

²²¹ John Rawls, *Political Liberalism*, 7.

Nussbaum's capabilities approach which states, "The basic institutions of society are to be arranged so as to assure, so far as reasonably possible, that each citizen reaches a threshold level of capability in each of the ten basic types of human capability."

A second principle, devised by Richardson to be lexically prior, but inclusive of Rawls's principles of justice which addresses human needs satisfaction in terms of primary goods, states, "The basic institutions of society are to be arranged so that, so far as reasonably possible, each citizen is assured a decent minimum of opportunity, income, wealth, and self respect." Richardson is unable to define any group whose motivations would lead them to choose this principle to precede Rawls's principles of justice. Because his perspective is that human needs cannot be satisfied by primary goods alone, he states:

As the facts of disability highlight, it does not seem plausible to interpret basic needs in terms of the primary goods. Accordingly, in relation to the motivational assumption, (this option) stands at an unstable point, attempting to recognize basic needs without drawing on an account of central human capabilities.²²²

The author is in complete agreement with the value added by the capabilities approach in that he agrees with the notion that focusing on the outcome of societally initiated action is essential and that failure to assure that the distribution of goods or the organization of assistance and dissemination of information delivers the desired human flourishing is folly. He also would like to address the seemingly impossible expectation that a government assure inclusive and democratic norms, tolerant and mature attitudes, or beneficial relationships. In defense of Rawls's primary goods position, the distribution

²²² Henry S. Richardson, "Rawlsian Social-Contract Theory": 436-437, 453.

of economic goods such that people with impairment are able to purchase appropriate transportation and personal care assistance, such that public spaces are rendered barrier-free, such that technology supports their employment, and such that educational supports are in place, will lead to increased inclusion and visibility in the community. This, in turn, will lead to an increased comfort, tolerance, and maturity in society that will, in addition to the distribution of economic goods, improve the capabilities of people with impairment. Richardson, himself, makes a statement, which references his addition of the clause “as far as is reasonably possible” in his principles of justice as stated above.

He says:

The hedge embodied in the clause about what is ‘reasonably possible,’ in this principle seems the price we have to pay within Rawls’s contractarian scheme for refusing to postpone issues about disability to the legislative stage in which the parties know the level of the resources of the society in which the persons they represent reside.²²³

It seems to the author that this statement acknowledges the role economic goods play in a society’s facilitation of goods, even heterogeneous goods which lead to the capabilities.

What does Nussbaum think of Richardson’s effort? She says, “...my basic response to Richardson’s paper is: ‘Yes. That’s right. If you really changed all that, we would be in business.’”²²⁴ She goes on to state that while Richardson’s offering has merit, it cannot claim identification with justice as fairness or even the social contract tradition as a whole. She says:

²²³ Henry S. Richardson, “Rawlsian Social-Contract Theory”: 433.

²²⁴ Martha C. Nussbaum, “Replies,” *The Journal of Ethics* 10 (2006): 492.

What I think needs bringing out very clearly, since Richardson is mining Rawlsian ideas for insight on this question, is how dramatically one must depart from classical social contract doctrine in order to have an adequate answer to questions about justice and disability. One has to give up, that is, two parts of the tradition to which Rawls attached much importance: the idea of the ‘circumstances of justice’ as involving similar physical and mental powers, and the related idea of mutual advantage as the goal of the contract.²²⁵

Nussbaum points out another departure in Richardson’s assumption that identifies individuals in the original position as trustees for people with impairment. She says:

Of course Richardson is as aware as I am that Rawls himself did not make that move: the parties are trustees for citizens’ in the Well-Ordered Society, who are characterized, in rather idealized terms, as ‘fully cooperating members of society over a complete life,’ a characterization that, as Rawls explicitly says, excludes people with severe disabilities, both physical and mental.²²⁶

She also takes issue with Richardson on his translation of her theory into a procedural model. She says:

The part of Richardson’s argument in which he compares the simple Nussbaumian view to mixed views is difficult for me to assess, since I think and argue, that there is a great difference between procedural and outcome-oriented views and so I feel that it is not quite sufficient to treat the simple Nussbaumian view as if it were one more example of a procedural view.²²⁷

In *Frontiers of Justice*, she says:

The deepest difference between the capabilities approach and Rawlsian contractarianism lies in its basic theoretical

²²⁵ Martha C. Nussbaum, “Replies”: 495.

²²⁶ Martha C. Nussbaum, “Replies”: 496.

²²⁷ Martha C. Nussbaum, “Replies”: 501.

structure. Rawls's approach, like most social contract doctrines, is a procedural approach to justice. In other words, it does not go directly to outcomes and examine these for hallmarks of moral adequacy. Instead it designs a procedure that models certain key features of fairness and impartiality, and relies on these procedures to generate an adequately just outcome.²²⁸

Nussbaum fails to take into account Rawls's use of "reflective equilibrium." In *A Theory of Justice*, Rawls describes a method for assuring that the principles chosen in the original position will facilitate the desired outcome. He says:

We can note whether applying these principles would lead us to make the same judgments about the basic structure of society which we now make intuitively and in which we have the greatest confidence; or whether, in cases where our present judgments are in doubt and given with hesitation, these principles offer a resolution which we can affirm on reflection. There are questions which we feel sure must be answered in a certain way. For example, we are confident that religious intolerance and racial discrimination are unjust. We think that we have examined these things with care and have reached what we believe is an impartial judgment not likely to be distorted by an excessive attention to our own interests. These convictions are provisional fixed points which we presume any conception of justice must fit. But we have much less assurance as to what is the correct distribution of wealth and authority. Here we may be looking for a way to remove our doubts. We can check an interpretation of the initial situation, then, by the capacity of its principles to accommodate our firmest convictions and to provide guidance where guidance is needed.

In searching for the most favored description of this situation we work from both ends. We begin by describing it so that it represents generally shared and preferably weak conditions. We then see if these conditions are strong enough to yield a significant set of principles. If not, we look for further premises equally reasonable. But if so, and these principles match our considered convictions of

²²⁸ Martha C. Nussbaum, *Frontiers of Justice*, 81.

justice, then so far well and good. But presumably there will be discrepancies. In this case we have a choice. We can either modify the account of the initial situation or we can revise our existing judgments, for even the judgments we take provisionally as fixed points are liable to revision. By going back and forth, sometimes altering the conditions of the contractual circumstances, at others withdrawing our judgments and conforming them to principle, I assume that eventually we shall find a description of the initial situation that both expresses reasonable conditions and yields principles which match our considered judgments duly pruned and adjusted.²²⁹

Rawls does not, as Nussbaum suggests, design “a procedure that models certain key features of fairness and impartiality,” and then rely “on these procedures to generate an adequately just outcome” without putting that procedure through vigorous challenges, revisions, and review.

Nussbaum goes on to give the argument for her preference for an outcome-based approach. She says:

Defenders of outcome-oriented views are likely to feel that procedural views put the cart before the horse: for surely what matters for justice is the quality of life of people, and we are ultimately going to reject any procedure, however elegant, if it doesn’t give us an outcome that squares well with our intuitions about dignity and fairness.²³⁰

The author points out that Rawls would agree as evidenced by his attention to reflective equilibrium. The procedural framework, furthermore, once identified, allows each citizen, who lacks hindsight with its *ex post facto* information at the outset of an inquiry, an established method for arriving at just decisions. Outcome-based evaluations depend

²²⁹ John Rawls, *A Theory of Justice*, 17-18.

²³⁰ Martha C. Nussbaum, *Frontiers of Justice*, 82-83.

on results. Without a procedural framework, how are policies initially formulated and should not nascent principles aim for maximal justice?

Nussbaum also notes that, in order to accommodate people with severe impairment, Richardson's notion of self-respect must differ in a profound way from that of Rawls. Rawls's notion of self-respect is entwined with the idea of the "self-confidence of the equal citizen. Thus it presupposes the development and exercise of both moral powers and therefore an effective sense of justice."²³¹ Richardson, on the other hand, defines self-respect as "an attitude that 'is necessary for all people, no matter what their level of ability or disability, to have a sense that their life is worth living.'"²³²

Nussbaum's rebuttal to Richardson brings this work to a critical question—one that needs attention as a prelude to the author's attempt to formulate his revised model. What is the essence of justice as fairness? What must a revised version incorporate if it is to be recognized as basically Rawlsian?

²³¹ Martha C. Nussbaum, "Replies": 499.

²³² Martha C. Nussbaum, "Replies": 499.

Chapter Five

A Response to Rawls's Challenge on Impairment

*Ain't it strange the way we're ignorant
How we seek out bad advice
How we jigger it and figure it
Mistaking value for the price...—Paul Simon, So Beautiful
or So What*

Will the inclusion of people with severe cognitive and physical impairment in the original position alter justice as fairness beyond recognition? Would Rawls acknowledge the revised version as within his vision? Although he postpones consideration of people with severe impairment until the legislative phase, Rawls states that justice as fairness is to be seen as a preliminary model, simplified initially for the general case, but with the understanding that impairment will be grappled with in a future, more developed version. Unfortunately, Rawls died before a thorough review of the theory was addressed. Critiques from other philosophers regarding the problem of impairment, mentioned in the earlier part of this work, were made, in general, after his death. Contemplation of what Rawls would agree to or reject if he were alive today is speculative at best. He left a body of work and stated perspectives, which speak for him. Anything added, subtracted, or revised can be said to be neo-Rawlsian at best. With that understanding, it nonetheless

is possible to consider revision in light of Rawls's known mission and positions. In

Political Liberalism Rawls states:

Since we begin from the idea of society as a fair system of cooperation, we assume that persons as citizens have all the capacities that enable them to be cooperating members of society. This is done to achieve a clear and uncluttered view of what, for us, is the fundamental question of political justice: namely what is the most appropriate conception of justice for specifying the terms of social cooperation between citizens regarded as free and equal, and as normal and fully cooperating members of society over a complete life?

By taking this as the fundamental question we do not mean to say, of course, that no one ever suffers from illness and accident; such misfortunes are to be expected in the ordinary course of life, and provision for these contingencies must be made. But given our aim, I put aside for the time being these temporary disabilities and also permanent disabilities or mental disorders so severe as to prevent people from being cooperating members of society in the usual sense. Thus, while we begin with an idea of the person implicit in the public political culture, we idealize and simplify this idea in various ways in order to focus first on the main question.

Other questions we can discuss later, and how we answer them may require us to revise answers already reached.²³³

Thus, Rawls is open to revision and seems to have intended a review and possible adjustments to justice as fairness. Between the time of Rawls's original writing and today, disability activism has forced open previously closed doors and, like other civil rights movements, has made its agenda unavoidable. But, in addition to the obvious primary concern for inclusive justice, the author questions whether justice can be achieved for anyone without a comprehensive consideration of possible scenarios that

²³³ John Rawls, *Political Liberalism*, 20.

might affect, and probably will affect in some way, any participant during the course of her complete life. He suggests that the exclusion of people with severe impairment from the original position, along with consideration of their circumstances, is among those components requiring revision. At this point, the author would like to re-envision the activity in the original position and see how this revision might appear.

It is agreed that choosers, in the original position, will be rational individuals acting as trustees for every possible member of society. They will be veiled from their individual circumstances, characteristics, and beliefs, in Rawlsian fashion. But they will also be conscious that impairment will most likely play some role in every life and that that there is a 15.3 % chance globally that moderate or severe impairment will affect one's future self or one's children and grandchildren.²³⁴ From that perspective, rational choosers will determine whether their own self-interest compels them to consider the issues of impairment in the original position.

People in the original position, while they know that they themselves are not severely impaired in that moment, have no knowledge of the circumstances of their children or grandchildren. Nor do they know what their future cognitive and physical status will be. This author assumes that a person, under the veil, will represent the interests of progeny and one's future self, who might have impairment, based on seeing them as extensions of self. Rawls discusses a related concept in his notion of "heads of families." He says:

The question arises, however, whether the persons in the original position have obligations and duties to third

²³⁴ Colin Mathers, Ties Boerma, and Doris Ma Fat, *The Global Burden of Disease: 2004 Update* (World Health Organization Press: Geneva, Switzerland, 2008), 34.

parties, for example, to their immediate descendants. To say that they do would be one way of handling questions of justice between generations. However, the aim of justice as fairness is to try to derive all duties and obligations of justice from other reasonable conditions. So, if possible, this way out should be avoided. There are several other courses open to us. We can adopt a motivation assumption and think of the parties as representing a continuing line of claims. For example, we can assume that they are heads of families and therefore have a desire to further the well-being of at least their more immediate descendants. Or we can require the parties to agree to principles subject to the constraint that they wish all preceding generations to have followed the very same principles. By an appropriate combination of such stipulations, I believe that the whole chain of generations can be tied together and principles agreed to that suitably take into account the interests of each. If this is right, we will have succeeded in deriving duties to other generations from reasonable conditions.²³⁵

The author believes that a person, under the veil, will represent the unknown and unknowable circumstances of future generations and his own future self, not only as an obligation or duty, nor even from the perspective of a concerned patriarch or matriarch, but as a self-interested contractor. This belief is rooted in the notion that self-concept extends beyond the present self with its physical, intellectual, and emotional components. People are passions and beliefs as much as body-delimited selves. People find meaning in working toward goals, which will far outlive their existences. The author does not want to argue whether people do anything from a selfless perspective or whether every action is undertaken for a personal reward, but he can say with certainty that beyond any altruistic motive, there is additionally an expectation of personal gain, even if psychologically veiled, in every action. It makes a person feel good about himself to teach at-risk children. A person feels that in working toward a cure for cancer, her own

²³⁵ John Rawls, *A Theory of Justice*, 111.

medical battle has meaning. Often good deeds are done simply because internalized self-expectations make a failure to perform inconceivable. Acting through a strong sense of empathy means that if others suffer, the empathizer also suffers. Thus, a person may act in ways that affect other people and things beyond what can immediately be identified as self-interest, but it is because they self-identify in some important way with the objects of their actions and so their actions represent rational self-interest. So, rational choosers in the original position can represent those with severe cognitive impairment in the same spirit they represent themselves, yet the important question of self-representation still needs to be explored.

How can principles of justice be developed by participants who fail to meet the criteria of rationality and reasonableness? The author acknowledges that designing a just society requires both the ability to reason and the willingness to universalize decisions, but insists that all people, including those with severe cognitive impairment, be self-represented in the original position by having a participatory role in the formation of basic social structures, even if the representation is not in *classically* active ways (rational bargaining).

When the author first encountered his hepatologist's shocking perspective on the question of treatment, the doctor was bewildered to hear that the author would choose to undergo chemotherapy for his hepatitis C infection. He assumed the author's life was of such a poor quality that the difficult and painful struggle to save it would be declined. Frankly, the doctor's perception of how the author felt about his life was so intensely inaccurate that it raised the question of how non-impaired participants in the original position can represent an impaired perspective without any personal experience.

Another story about a non-verbal adolescent with autism named Jonathan Lerman provides additional insight into misconceptions. Jonathan often behaved so inappropriately that his parents frequently received calls from school requiring their intervention. They were surprised when one day Jonathan's aide summoned them for a joyous reason. Jonathan had found some charcoal and pastels and was drawing. He was creating figures, which were so emotive that they revealed, according to his parents, "...the inner thoughts and feelings of a child whose emotions we could only speculate about until then. In that instant, we went from knowing that we had a significantly handicapped child to realizing that we had an extraordinarily gifted child."²³⁶ Caren and Alan Lerman state, "It has long been widely believed that children with autism do not comprehend the emotional states of others and, indeed, may be extremely limited in their ability to understand or experience their own emotional states."²³⁷ But Jonathan's artistic breakthrough demonstrates that, at least for him, and perhaps for many non-verbal people with autism, intense feelings exist in an unexpressed state. Through his art, Jonathan provides:

...a window into his heart. He brings us to the core of his being and shows us the anguish and triumphs he experiences. People come alive in his drawings, their emotional expressions delineated by his bold beautiful lines. Jonathan's portraits have an intensity that is extraordinary. His observations are so acute, telling us he knows far more than we realize and allowing us to confront the lonely isolated world he inhabits.²³⁸

²³⁶ Caren and Alan Lerman, afterword to Lyle Rexer, *Jonathan Lerman: Drawings by an Artist with Autism* (New York, New York: George Braziller, Inc., 2002), 126.

²³⁷ Caren and Alan Lerman, afterword to Lyle Rexer, *Jonathan Lerman: Drawings*, 126.

²³⁸ Caren and Alan Lerman, afterword to Lyle Rexer, *Jonathan Lerman: Drawings*, 126.

Somehow, the authentic experiences and circumstances of people with severe impairment must inform the choices made in the original position. The testimony of family and allies provides some valid information. But, if decisions in the original position are left to those who can reason, and the nature of decision-making affords no possible alternative, how can people with severe cognitive impairment have a direct influence on the design of their society? Political participation, at first glance, appears to require advanced reasoning capability, but demonstration of extraordinary needs of individuals with impairment alone can catalyze new societal questions, which ultimately lead to answers, just as much as the cognitive input of a reasoning individual.

In 2002, the Colorado Legislature considered a cost-saving proposal to eliminate a Medicaid benefit that situates a private duty nurse within the home of a person with severe impairment, who is dependent on medical technology, such as a ventilator, to live. Many of these clients have cognitive involvement as well. This program frees individuals from the hospital setting and allows them to live with their families, within the community. It also saves Medicaid monies as home-based private duty nursing is less expensive than hospital-based care. Failing to appreciate this fact, some legislators sought to eliminate the program for the over one hundred patients, mostly children, which it serves. Family members and advocates, accompanied by about twenty children arrived at the Colorado Capitol building to testify against the elimination of the program. The voiceless children's gurgling suction machines and sighing ventilators testified and their argument proved undeniably compelling. The program survived. Were not these children essential, active participants in a political outcome that affected their wellbeing

even though they were not rational bargainers?²³⁹ Were they not active participants, providing self-representation, despite not having prepared any material, spoken one word, or understood the nature of the agenda?

Any revision that removes the exclusivity of the criterion of rationality from justice as fairness involves such a departure, not only from traditional readings of Rawls but from contract tradition and even much of traditional political theory in general, that the origins of the mandate must be reviewed and dissected to investigate whether its inclusion is so crucial to justice as fairness that its modification will render the theory unrecognizable. Why did Rawls insert the criterion of rationality into justice as fairness? The author thinks, in part, that Rawls's work, as part of a continuum of contract theories—collections of philosophical narratives that define a participant as a thinking being—simply fell into place with some unnecessary vestiges that must fall away with the reconsideration of the theory as it pertains to impairment.

Rawls speaks at length of Kant's influence, and while Kant's extreme position on the singular essentiality of rational thought must be replaced, important Kantian concepts must be maintained, even in an inclusive theory. The author wishes to maintain the Kantian position that autonomy is a primary good and should be maximized to the greatest extent possible. Autonomy should not be a requirement for participation, but the author would argue that its maximal acquisition is the foundation for self-respect for every human being.

Rawls's integration of Kant's categorical imperative in the device of the veil of ignorance is essential to justice as fairness, and when Rawls discusses Kant's influence in

²³⁹ Interview with Christine Russell, family Medicaid advocate, March 1, 2009.

the fortieth section of *A Theory of Justice*, he emphasizes the importance of Kant's ethic of reciprocity. Yet, Kantian theory states that non-reasoners fall outside the parameters of people to whom rational citizens have a moral obligation to justice due to their inability to reciprocate. This perspective cannot be carried into an inclusive theory and so it is not the valuing of reason that is problematic in Kant, but rather the lack of valuing of all other human characteristics.

The historical association of qualification for participation with the ability to reason speaks to a perennial desperation in humans to self-define as separate from other animals—having transcendence and dominion over the animal, both without and within. Kant carries ratio-centrality to a rare extreme. The rational aspect of humans is described as godlike. Humans can contemplate and ascertain God's will but, in accordance with the Enlightenment project, make decisions independent of God. Human reason allows action with intent, thus identifying responsible actors. It allows a person to understand and accept the duties required of a citizen, reciprocating and cooperating with others, thus enabling community. The author agrees that reason is the generator of responsibility, motivation, and execution, but valuable extra-rational traits are essential to community as well and must also be considered when determining the qualification of participants. The author does not believe that the essence of justice as fairness relies on a Kantian categorization of citizens into distinct passive and active participants. In real life, these differentiations do not exist so cleanly and people move up or down the continuum of rational decision-making at different times of their lives and even in different choice-making circumstances. Active citizenship is a fluid status that defies distinct categorization. Only those at the furthest end of non-rationality on the rationality

continuum have no instances in their lives of active choice-making. The author wishes to replace Kant's position that demands rationality as a criterion for "civil personality" and hence moral consideration and rights-bearing status with a criterion of contribution.

Rawls does define his participants as "fully cooperating" but the author would like to make the argument that cooperation, defined as humans interfacing with one another to the betterment of both, is very similar to participants making contributions, which enhance the wellbeing of individuals and community. Both establish relationships based on mutual advantage, though the latter may lack intent. The author would define contribution as a human act, sometimes intentional and sometimes without intent, which enhances social wellbeing in a variety of ways. One can be socially cooperative by participating in the mutual protection of body, property, and freedoms through submission to an independent legal authority, by lending one's unique skills to the accomplishment of projects requiring diverse abilities, or by participating in the economic and political life of society—all classical interpretations of contribution. He would also say, however, that one makes a social contribution by lending one's unique perspectives and experiences to the social fabric and acknowledging the value in like contributions made by others. A person might contribute by sharing, through words or demonstration, his life experience to broaden society's awareness of what the infinite possibilities of human existence encompass. In the case of a person with severe impairment, that sharing exposes the listener to an experience, which potentially could become any human's story, and in this case, the story can generate fear and denial. Thus an intransigent problem emerges.

Rawls is right when he posits that humans are risk-averse. Their seemingly daring, imprudent, and rash behavior is due not to their risk-taking natures but rather to their propensity for willful ignorance. The veil of ignorance is necessary to ensure that “no one is advantaged or disadvantaged in the choice of principles by the outcome of natural chance or the contingency of social circumstances,” but, if people were willing to acknowledge that humans are universally susceptible to impairment and that it inevitably touches every life, perhaps the very truth of corporeal fragility would manifest in justice for people with impairment, even without the veil.²⁴⁰ But, because people with severe impairment have been sequestered by those who prefer not to acknowledge reality, the artificial device of the veil remains essential. People with severe impairment, allowed full access to community, are finally at their most valuable to broader society when they force the risk-averse human to accept how little separates the handsome, brilliant, valedictorian from the confused and dependent example of one’s worst fears. Finally, all are people with human needs housed within vulnerable objects of entropy. Only the familiarity born of inclusion will penetrate the fear-generated denial of the essential universality of vulnerability inherent in the human condition.

If people with severe impairment are excluded from the original position, all of the possible human circumstances and characteristics will not be considered and the completed design will leave the entire citizenry vulnerable in each person’s potential for severe impairment and the inherent challenges that status entails if unaddressed by fundamental social policy. When Rawls states that the exclusion of a tiny portion of people from the original position is not a “serious practical problem,” he neglects to

²⁴⁰ John Rawls, *A Theory of Justice*, 11.

acknowledge that the exclusion extends to the entire citizenry in potential circumstances.²⁴¹ Attention to the circumstances of people with severe impairment in the original position, coupled with the universal potential for each person in society acquiring this status in their lifetime is the primary reason inclusion of people with severe impairment is mutually advantageous. But, there are many other ways integration enhances social wellbeing.

Excluding people with severe impairment, in an effort to live only among clones (rough equals), denies society the opportunity to grow and transcend. If a person's circumstances involve poverty, prejudice, injustice, or dependence and if that person's community identifies with those circumstances, acknowledging and accepting the inconveniences, expenditures, and guilt while still pushing toward ever increasing justice instead of imposing isolation—that is societal transcendence. This transcendence leads to successes, achieved with difficulty, which lead to an increased sense of power, both personal and societal, and so to an increased confidence in tackling the next challenge.

Living with diversity also helps to erase assumptions and build true understandings in their place. If true understandings hold sway, Peter Singer will accept the disability community's perspective as more valid than his assumption-ridden own. Jerry Lewis will no longer hold pity parties perceiving instead the shared humanity of people with muscular dystrophy more than their brokenness. Care theorists will understand that reciprocity of a kind *does* infuse the relationship between caregiver and care recipient and that many important insights can be gleaned from the experience. People can focus on finding the real villains instead of scapegoating those who are

²⁴¹ See note 215.

benignly different. In the long run, reality is always superior to delusion. Delusion leads to lost opportunities and wasted time. More importantly, delusion leads to false hierarchies and these, ultimately, only benefit those in the temporarily loftiest position.

Contributions made to society by people with severe impairment also include the enhancement of experience garnered by those who, by living with people for whom achievement comes with great difficulty, appreciate, rather than take for granted, each small aspect of any good. What is valuable is not the good itself, but rather, the **experience** of the good. People will experience a richer manifestation of a good if it is not taken for granted. This is related to an Iranian citizen risking life and limb to vote as opposed to an American citizen being “deterred” by a rainy day or a busy schedule.

Resisting difference is also denying the benefits of exposure to diverse ways of thinking, problem solving, and finding meaning. An older sister observes her intellectually impaired brother in his total immersion with watching a beetle, or vacuuming the carpet, or eating ice cream and realizes how encumbered her life is with concern over the future, her image, competition, and the expectations of others. He has unintentionally provided her with an alternative perspective.

Finally, does society value maturity? The road from infancy to adulthood is generally characterized by an evolution from egocentricity to empathy and sacrifice. It follows that the idealization of pure pleasure or happiness, where people with severe impairment are seen as a negative influence on the wellbeing of society, embodied by Singer’s perspective, lacks maturity in its basic metric of wellbeing. If full inclusion, with awareness of the valuable contributions made by people with severe impairment, comes to pass, society will have the opportunity to move beyond immaturity into a

position of evolved development. The possible benefits could be extraordinary. Thus, the author feels that the concept of mutual advantage need not be eliminated from justice as fairness in this process of revision. Inclusion of people with severe impairment is completely compatible with mutual advantage. Hume says,

Men being naturally selfish, or endowed only with a confined generosity, they are not easily induced to perform any action for the interest of strangers, except with the view to some reciprocal advantage, which they had no hope of obtaining but by such a performance...All this is the effect of the natural and inherent principles and passions of human nature; and as these passions and principles are inalterable, it may be thought that our conduct, which depends on them, must be so too, and that it would be in vain, wither for moralists or politicians, to tamper with us, or attempt to change the usual course of our actions, with a view to public interest.²⁴²

Even if it is acknowledged that generosity and self-sacrifice are part of human nature, since their application is neither universal nor ubiquitous, it remains important to assume cooperation only if it can be established that both parties will gain from the transaction, as Hume suspects. The author, in establishing the value of extra-rational contribution, has justified the maintenance of mutual advantage in justice as fairness. Despite the continued applicability of mutual advantage, Hume's influence in other ways has a deleterious effect on Rawls's effort as pertains to people with severe cognitive impairment.

Rawls mentions his incorporation of Hume's circumstances of justice into his theory. He discusses that justice can only operate in conditions of relative scarcity, being unnecessary in conditions of abundance and unsustainable in conditions of extreme

²⁴² David Hume, *A Treatise of Human Nature*, (Mineola, New York: Dover Publication, Inc., 2003), 370-371.

scarcity with the inherent desperation anticipated. This portion of the circumstances of justice continues to make sense, even with the inclusion of people with severe impairment. The second aspect is problematic. As discussed above, Hume assumes that humans will need to be rough equals in order to withstand the opposing interests of other bargainers. Rawls incorporates this notion saying:

...although a society is a cooperative venture for mutual advantage, it is typically marked by a conflict as well as an identity of interests. There is an identity of interests since social cooperation makes possible a better life for all than any would have if each were to try to live solely by his own efforts. There is a conflict of interests since men are not indifferent as to how the greater benefits produced by their collaboration are distributed, for in order to pursue their ends they each prefer a larger to a lesser share.²⁴³

Rawls continues, saying, “These individuals are roughly similar in physical and mental powers; or at any rate, their capacities are comparable in that no none among them can dominate the rest,” in order to prevent coercion or violence as an outcome of this propensity.²⁴⁴ With these statements, Rawls conforms to Hume and is unable to conceive of justice in a society peopled with wildly diverse abilities. For this reason among others, there are no people with impairment in Rawls’s original position.

Confusion exists in that Rawls speaks of the original position as both a starting point and a point of ongoing deliberation. It may represent the hypothetical point in time where society is starting from scratch and developing the principles of social cooperation but it does not describe the civilizing of a people leaving the state of nature as does Hume’s contracting scenario. Justice as fairness, according to Rawls, also has an

²⁴³ John Rawls, *A Theory of Justice*, 109.

²⁴⁴ John Rawls, *A Theory of Justice*, 109-110.

immediate and ongoing nature and is meant to be seen as a template for each social decision made in the course of a lifetime. In justice as fairness, once under the veil (either as an original position or a state of mind assumed for the purposes of ongoing decision making) each participant acts as a trustee for the interests of all. When the original position is assumed for the purpose of assuring ongoing justice, the state of nature is long dissolved and humans are already in community, using the template of the principles of justice to develop and maintain the most just social system possible.

While Rawls does not deliver an anthropological account of people leaving the state of nature, problems involving the circumstances of justice and their incorporation into justice as fairness would only occur in a timeframe between the state of nature and the original position and then only if Rawls's theory is considered a contemporary manifestation of earlier contract theories where mutual advantage is seen in a narrow, classical context. From this position, contractors might be unwilling to enter into community with people whose value has not necessarily been ascertained and whose expense would defy mutual advantage. Once, however, in the original position, given information about the prevalence of impairment and the mutually advantageous nature of including the impairment perspective, designers will invite participation and representation of those previously excluded. If the original position is taken as an ongoing perspective and participants are inclusive of people with impairment, who already have a seat at the table, it seems that Humean constraints surrounding rough equality are unnecessary vestiges of earlier contract theory, where decision making only pertains to the initial choice situation.

Once designers are veiled and faced with the reality, through given information, (the author imagines designers restrained in seats with eyelids mechanically held open as in *A Clockwork Orange*, so adverse to reality are they) that every single human being, without exception, is vulnerable to impairment in their lifetime, that their children or grandchildren, at that very moment, may exist in an impaired state, and that consideration of the interests of impaired citizens mirrors potential self-interest, the author believes that rough equality will hold no sway. What good is rough equality in the moment when that equality (in the case of impairment) is so ephemeral?

Rawls, however, also displays an interest in the agreed-upon design maintaining stability after the veil is lifted. In *Political Liberalism* he considers:

...how the well-ordered democratic society of justice as fairness may establish and preserve unity and stability given the reasonable pluralism characteristic of it. In such a society, a reasonable comprehensive doctrine cannot secure the basis of social unity, nor can it provide the content of public reason on fundamental political questions. Thus, to see how a well-ordered society can be unified and stable, we introduce another basic idea of political liberalism to go with the idea of a political conception of justice, namely, the idea of an overlapping consensus of reasonable comprehensive doctrines.²⁴⁵

A political conception of justice is a publically agreed upon model for adjudicating between the interests of liberty and equality. Rawls comments on the fact that citizens in society, hold “deeply contested ideas about how the values of liberty and equality are best expressed in the basic rights and liberties of citizens so as to answer to the claims of both

²⁴⁵ John Rawls, *Political Liberalism*, 133-134.

liberty and equality.”²⁴⁶ The goal of justice as fairness is to provide a model of just adjudication. In the original position, divested of all personal identity and acting as trustees for all humans with their varied characteristics, designers come to consensus easily, but once unveiled, their diverse doctrines, faiths, cultural histories and philosophies reemerge. Per Rawls:

Religious and philosophical doctrines express views of the world and our life with one another, separately and collectively, as a whole. Our individual and associative points of view, intellectual affinities, and affective attachments, are too diverse, especially in a free society, to enable those doctrines to serve as the basis of lasting and reasoned political agreement. Different conceptions of the world can reasonably be elaborated from different standpoints and diversity arises in part from our distinct perspectives.²⁴⁷

Despite the many diverse positions found in the unending line of doctrines, which populate the world and even the community, Rawls believes, in the tradition of Rousseau and the general will, that there will be overlapping consensus on the principles of justice—those ideas that all reasonable and rational people will agree upon. He confirms that justice as fairness will not be bent “to existing unreason” where “doctrines that are not only irrational but mad and aggressive” might interfere with consensus.²⁴⁸ Thus, Rawls believes that the product of the original position—the principles of justice—comprising the lexically prior principle of equal liberty and the difference principle,

²⁴⁶ John Rawls, *Political Liberalism*, 4.

²⁴⁷ John Rawls, *Political Liberalism*, 58.

²⁴⁸ John Rawls, *Political Liberalism*, 144.

conceived by Rawls without the participation of people with severe impairment, will survive the unveiling.

But, it must now be considered whether Rawls's principles of justice derived from the original position and the assumption that an overlapping consensus of reasonable comprehensive doctrines will manifest in maintenance of those principles—can survive the addition of a group of people with extraordinary needs and highly divergent experiences—people with severe impairment. The author believes they can. In fact, the application of the principles of justice to people with severe impairment might be maintained without regard to the mandate of reasonableness. It is important to note that impairment has the unique feature of demanding universal attention, even once the veil is lifted and the designers become aware of their individual circumstances. Once aware of their actual circumstances, they might know that they will never be female, never be a refugee, never be untouchable or inescapably impoverished, never be a person of color or adhere to an outcast doctrine, *but they will never know that they are immune to impairment*. Not under the veil, and not once the veil is lifted.

Epilogue

Early in 2004, my father received the John Evans Adjunct Professor of the Year Award from the University of Denver. The award's recipient is determined through student lobbying, and provides testimony of his commitment to young people and their appreciation of his passion. He was always eager to do whatever it took to engage his students whether that required clowning, which generally involved a relinquishment of all personal dignity, individual tutoring, or recording his lessons on tape for students with learning disabilities. He was charismatic and beloved. He never missed one class for illness. but that was not to say he was never ill, only that he lived in an optimistic bubble of belief that acknowledging illness meant you were ill, while ignoring the occasional cold or flu translated into health. He would often joke that he planned to live to be one hundred and twenty.

On Easter evening some three years later, my mother, who was working in a separate part of the house from my father, heard the phone ring. On the line was my sister-in-law in Rhode Island, who blurted out that my father must be located immediately because something was very wrong. He had called my brother's home by pushing the redial button on his cell phone, even as he was lying on the floor, unable to move his right side or speak with any clarity or volume. He had literally been felled by a

severe hemorrhagic stroke and was immediately rushed to the hospital. During the ensuing weeks, while he was comatose in the intensive care unit, the hospital received so many phone calls, inquiring about his status, so many crying and concerned visitors, that they asked whether he was a celebrity.

During those catastrophic weeks, my known father died and a new one was born. The new one can no longer beat everyone at Scrabble or remember most of his former life. He cannot lead the Seder or make his famous haroset. He cannot tell his outrageous stories or romp with the dogs through the snow. I will now never fully know the specifics of my ancestry, which was a matter of ongoing discussion before the stroke and, while my father still remembers much of the ancient history he loved, he is often fuzzy and unsure. The man, who packed forty-three boxes of books for a move to his current home, can no longer read.

Five years post-illness, he is rarely visited or called. People quickly got on with their lives and it is frustrating to try to communicate with him. It is also possible that he reminds people of their own vulnerabilities. When I ask my mother how she soldiers on day after day, knowing she feels angry, scared, abandoned, and exhausted, she tells me she just pays attention. Through the harshness, there are moments of learning and enjoyment. Yes, she is angry that he didn't face the possibility that uncontrolled high blood pressure could severely alter so many lives. Yes, she would like to sleep more and work less. Yes, she struggles with the weight of overwhelming responsibility. But she chuckles when she overhears my father teaching Hebrew to his physical therapist, forced to make his partially paralyzed mouth articulate in order to assure correction of mispronounced words. She is pleased that she has maintained the garden when she sees

him outside, watching a hummingbird drinking from the butterfly bush or waiting for the bluebird fledglings to fly from the birdhouse that was his Father's Day present. She is astounded by the grace with which her formerly hyperactive husband has accepted such a quiet and slow new life. The stroke also left him with severe sensory integration problems. He struggles with the sensation of water during a shower. During one frustrating moment, as she watched him grimacing as he rinsed his soapy face, she inquired, "Whatever happened to the man who swam in the ocean with me?" "He drowned," was the sarcastic response. The remodeled husband provides the occasional witticism.

In many ways this father is not the familiar childhood father. A comparison between the two invites a sense of loss because much of the previous father is gone. It is as if he has entered a time machine and returned to the culture and customs of his orthodox Jewish childhood, a place in time far prior to his mellowing and my birth. He speaks primarily German and Hebrew, both initial languages, lying untouched on the unaffected right side of his brain. His desk used to resemble a demolition site, while now he is obsessive about order and will spend a great deal of time cleaning a sink or picking dog hair off a chair. He is unparalleled at spot-the-differences games where the player compares two seemingly identical pictures and finds the tiny discrepancies and he excels in perfectly matching socks just out of the dryer. Not just in pairing the blue ones and brown ones, but in identifying the two that are older from the newly purchased pair of the same color. He is a different man—a man reincarnated within the same lifetime. The new man is still a man, however. He still wants to be recognized and respected. He still wants to have choices, make decisions, and be useful, and despite a severe cognitive

deficit, he can do these things and through their doing, live a life of self-respect and value.

I need to confess an important fact. When I began this work, six years ago, it was more of an intellectual exercise than the work of an advocate. I struggled, and still struggle, when interfacing with people with severe cognitive impairment. My own substantial physical impairment provides no level of familiarity or comfort in the non-rational world. In writing the chapter titled “Fear of Difference, Avoidance, and the Legacy of Isolation,” I was exploring my own unease. With the onset of my father’s illness, cognitive impairment came home, yet, even in this very personal case, I still stand on unfamiliar and sometimes uncomfortable ground. I often question my maturity in the matter, but maybe I simply lack adequate experience. While I certainly do not consider myself a champion of those with cognitive impairment, I do believe that my acknowledgement of personal deficiency prevents any return to disengagement. The journey of developing comfort and acknowledging common humanity moves forward. The same journey must occur with political theory as pertains to people with severe cognitive impairment. Society must move forward to comprehensive justice, inclusion, and community.

Bibliography

Anderson vs. Colorado, U.S. District Court for the District of Colorado, Case # 1:10-cv-01005-RBJ-KMT

Aquinas, Thomas. *Thomas Aquinas: Philosophical Texts*. Edited and translated by Thomas Gilby. Oxford, United Kingdom: Oxford University Press, 2003.

Aristotle. *Nicomachean Ethics*. Edited and translated by Martin Ostwald. Englewood Cliffs, New Jersey: Prentice Hall, 1962.

Asch, David A. "The Role of Critical Care Nurses in Euthanasia and Assisted Suicide." *New England Journal of Medicine* 334, no. 21 (May 23, 1996): 1374-1379

Bronston, William. "Institutions: Part 3." In *What We Have Done: An Oral History of the Disability Rights Movement*. Edited by Fred Pelka. Amherst, Massachusetts: University of Massachusetts, 2012.

Bronston, William. "Institutions: Part 4." In *What We Have Done: An Oral History of the Disability Rights Movement*. Edited by Fred Pelka. Amherst, Massachusetts: University of Massachusetts, 2012.

Buck v. Bell, 274 U.S. 200 (1927).

Chorover, Stephan L. *From Genesis to Genocide, The Meaning of Human Nature and the Power of Behavior Control*. Cambridge, Massachusetts: The MIT Press, 1980.

Colorado Cross Disability Coalition, d/b/a Center for Rights of Parents with Disabilities. *Fisher, et al v. Crawford, Saunders, M.D., P.C., et al*, Case No.: 2008CV3702. Found at <http://www.ccdonline.org/case/491>.

Colver, Allan, et. al. "Study Protocol: SPARCLE—A Multi-Centre European Study of the Relationship of Environment to Participation and Quality of Life in Children with Cerebral Palsy." *BioMed Central Public Health* 6 no. 105 (2006): 105-115.

Committee on the Elimination of Discrimination Against Women. Consideration of reports submitted by States parties under article 18 of the Convention on the Elimination of All Forms of Discrimination against Women: 5th periodic report of States parties: Israel. Mar 24, 2010. (CEDAW/C/ISR/5). Available online through <http://documents.un.org/>.

Committee on the Rights of Persons with Disabilities. *Implementation of the Convention on the Rights of Persons with Disabilities: Initial reports submitted by States parties under article 35 of the Convention: Hong Kong, China*. Feb. 11, 2011. (CRPD/C/CHN-HKG/1). Available online through <http://documents.un.org/>.

Convention on the Rights of the Child. *General Comment No. 9 (2006); the Rights of Children with Disabilities*. Feb. 27, 2007. (CRC/C/GC/9). Available online through <http://documents.un.org/>.

Coulter, David L. "Home is the Place: Quality of Life for Young Children with Developmental Disabilities." In *Quality of Life: Perspectives and Issues*. Edited by Robert A. Schalock. Washington, D.C.: American Association on Mental Retardation, 1990.

Daniels, Norman. "Justice and Long Term Care: Need We Abandon Social Contract Theory? A Reply to Nussbaum" In *Ethical Choices in Long-Term Care: What Does Justice Require?* Edited by Oni Annette LaGioia. Geneva, Switzerland: World Health Organization, 2002.

Donnelly, Jack. *Universal Human Rights in Theory and Practice*, 2nd ed. Ithaca, New York: Cornell University Press, 2003.

Drake, Stephen. "Not Dead Yet!" In *Peter Singer Under Fire: The Moral Iconoclast Faces His Critics*. Edited by Jeffrey A. Schaler. Peru, Illinois: Carus Publishing Company, 2009.

Edgerton, Robert B. "Quality of Life from a Longitudinal Research Perspective." In *Quality of Life: Perspectives and Issues*. Edited by Robert A. Schalock. Washington, D.C.: American Association on Mental Retardation, 1990.

Ervin, Mike. "Train of Regret." *New Mobility: Life on Wheels* 20, no. 194 (Nov. 2009): 40.

Ervin, Mike. "Blessed are the Butt-Wipers." *New Mobility: Life on Wheels* 8, no. 47 (Aug. 1997): 52.

Ervin, Mike. "Venting Time." *New Mobility: Life on Wheels* 19, no. 179 (August 2008): 42.

- Fink, Sheri. "Flu Nightmare: In Severe Pandemic, Officials Ponder Disconnecting Ventilators From Some Patients." *ProPublica*, Sep. 23, 2009.
<http://www.propublica.org/article/flu-nightmare-officials-ponder-disconnecting-ventilators-from-some-pat-923>.
- Freeman, Samuel. "Original position" In *The Stanford Encyclopedia of Philosophy*, last modified Dec. 20, 2008, <http://plato.stanford.edu/entries/original-position/>
- Frye, Lezlie. "Don't Dis-My Ability." In Garland-Thomson, Rosemary. *Staring: How We Look*. New York, New York: Oxford University Press, 2009.
- Garland-Thomson, Rosemarie. *Staring: How We Look*. New York, New York: Oxford University Press, 2009.
- Garland-Thomson, Rosemarie. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York, New York: Columbia University Press, 1997.
- Gauthier, David P. *Morals by Agreement*. New York, New York: Oxford University Press, 1986.
- Gaylin, Willard. Faulty Diagnosis: Why Clinton's Health-Care Plan Won't Cure What Ails Us." *Harper's Magazine*, October 1993: 57-64.
- Gewirth, Alan. *Human Rights: Essays on Justification and Applications*. Chicago, Illinois: University of Chicago Press, 1982.
- Gilbert, Alan. *Democratic Individuality*. Cambridge, United Kingdom: Cambridge University Press, 1990.
- Glendon, Mary Ann. *Rights Talk: The Impoverishment of Political Discourse*. New York, New York: The Free Press, a Division of MacMillan, Inc., 1991.
- Goode, David A. "Thinking About and Discussing Quality of Life." In *Quality of Life: Perspectives and Issues*. Edited by Robert A. Schalock. Washington, D.C.: American Association on Mental Retardation, 1990.
- Greene, Susan. "Greene: It was a life-altering decision, but who made it?" *Denver Post Online* (Denver, CO), September 9, 2010.
http://www.denverpost.com/ci_16027261?source=sb-facebook
- Heath, Dennis. "Self-Advocates." In *What We Have Done: An Oral History of the Disability Rights Movement*. Edited by Fred Pelka. Amherst, Massachusetts: University of Massachusetts, 2012.

- Hill, Thomas E. "The Importance of Autonomy." In *Autonomy and Self-Respect*. Cambridge, United Kingdom: Cambridge University Press, 1991.
- Human Rights Council. *Implementation of General Assembly Resolution 60/251 of 15 March 2006 Entitled "Human Rights Council*. Jan. 17, 2007 (A/HRC/4/75). Available online through <http://documents.un.org/>
- Human Rights Council. *Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary-General. Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities*. Jan. 26, 2009 (A/HRC/10/48). Available online through <http://documents.un.org/>
- Human Rights Council. Written Contribution by the Network of African National Human Rights Institutions to the Panel on national frameworks under article 33 of the Convention on the Rights of Persons with Disabilities. Feb. 24, 2010. (A/HRC/13/NI/8). Available online through <http://documents.un.org/>
- Hume, David. *A Treatise of Human Nature*. Mineola, New York: Dover Publication, Inc., 2003.
- Johnson, Harriet McBryde. *Too Late to Die Young*. New York, New York: Henry Holt and Company, LLC, 2005.
- Johnson, Harriet McBryde. "Unspeakable Conversations or How I Spent One Day as a Token Cripple at Princeton University." *New York Times Magazine*, Feb. 16, 2003.
- Kamm, F.M. "Famnine Ethics: The Problem of Distance in Morality and Singer's Ethical Theory." In *Singer and His Critics*. Edited by Dale Jameson. Malden, Massachusetts: Blackwell Publishers, 1999.
- Kania, Andrew Thomas. "The Scapegoat." *Catholica* (blog). http://www.catholica.com.au/andrewstake1/087_ak_120808.php
- Kant, Immanuel. *The Metaphysics of Morals*. Edited and translated by Mary Gregory. New York, New York: Cambridge University Press, 1996.
- Kant, Immanuel. *Political Writings*. Edited by Hans Siebert Reiss and translated by Hans Siebert Reiss and H.B. Nisbet. Cambridge, United Kingdom: Cambridge University Press, 1991.
- Keith, Kenneth D. "Quality of Life: Issues in Community Integration." In *Quality of Life: Perspectives and Issues*. Edited by Robert A. Schalock. Washington, D.C.: American Association on Mental Retardation, 1990.

- Keyserlingk, Edward W. "The Quality of Life and Death." In *Quality of Life: The New Medical Dilemma*. Edited by James J. Walter and Thomas A. Shannon. Mahwah, New Jersey: Paulist Press, 1990.
- Kingsley, Jason and Mitchell Levitz. *Count Us In*. New York, New York: Harcourt Brace, 1994.
- Kittay, Eva Feder. *Love's Labor: Essays on Women, Equality, and Dependency*. New York, New York: Routledge Press, 1998.
- Kittay, Eva Feder. "At the Margins of Moral Personhood." *Ethics* 116 (Oct. 2005): 100-131.
- Kittay, Eva Feder, Bruce Jennings, and Angela Wasunna. "Dependency, Difference, and the Global Ethics of Longterm Care." *The Journal of Political Philosophy* 13, no. 4 (2005): 443-469.
- Krantz, Susan L. *Refuting Peter Singer's Ethical Theory: The Importance of Human Dignity*. Westport, Connecticut: Praeger Publishers, 2002.
- Kristeva, Julia. *Powers of Horror: An Essay on Abjection*. New York, New York: Columbia University Press, 1982.
- Langer, Ellen J. and Benzion Chanowitz. "Mindfulness/Mindlessness: A New Perspective for the Study of Disability." In *Attitudes Toward Persons with Disabilities*. Edited by Harold Yuker. New York, New York: Springer Publishing Company, 1988.
- Lederberg, Joshua. "A Geneticist Looks at Contraception and Abortion." *Annals of Internal Medicine* 67, no. 3 (Sep. 1967): 25-27.
- Lerman, Caren and Alan Lerman. Afterword to Rexer, Lyle. *Jonathan Lerman: Drawings by an Artist with Autism*. New York, New York: George Braziller, Inc., 2002.
- Lifton, Robert Jay. *The Nazi Doctors: Medical Killing and the Psychology of Genocide*. New York, New York: Basic Books, 2000.
- Livneh, Hanoch. "A Dimensional Perspective on the Origin of Negative Attitudes Toward Persons with Disabilities." In *Attitudes Toward Persons with Disabilities*. Edited by Harold Yuker. New York, New York: Springer Publishing Company, 1988.
- Locke, John. *Two Treatises of Government*. Edited by Peter Laslett. Cambridge, United Kingdom: Cambridge University Press, 1988.

- Martinez, Connie. "A Dream for Myself." In *Quality of Life: Perspectives and Issues*. Edited by Robert A. Schalock. Washington, D.C.: American Association on Mental Retardation, 2009.
- Mathers, Colin, Ties Boerma, and Doris Ma Fat. *The Global Burden of Disease: 2004 Update*. World Health Organization Press: Geneva, Switzerland, 2008.
- McCarthy, Henry. "Attitudes That Affect Employment Opportunities for Persons with Disabilities." In *Attitudes Toward Persons with Disabilities*. Edited by Harold E. Yunker. New York, New York: Springer Publishing Company, 1988.
- McCormick, R.A. "To Save or Let Die: The Dilemma of Modern Medicine." In *Quality of Life: The New Medical Dilemma*. Edited by James J. Walter and Thomas A. Shannon. Mahwah, New Jersey: Paulist Press, 1990.
- Nedelsky, Jennifer. "Reconceiving Autonomy: Sources, Thoughts, and Possibilities." *Yale Journal of Law and Feminism* 1, no.1 (Spring 1999): 7-36.
- Nussbaum, Martha C. "Capabilities and Disabilities: Justice for Mentally Disabled Citizens." *Philosophical Topics* 30, no. 2 (Fall 2002): 133-166.
- Nussbaum, Martha C. "Replies." *The Journal of Ethics* 10 (2006): 463-506.
- Nussbaum, Martha C. *Beyond the Social Contract: Toward Global Justice*. Found at http://www.tannerlectures.utah.edu/lectures/documents/volume24/nussbaum_2003.pdf.
- Nussbaum, Martha C. *Frontiers of Justice: Disability, Nationality, Species Membership*. Cambridge, Massachusetts: The Belknap Press of the Harvard University Press, 2006.
- Nussbaum, Martha C. *Sex and Social Justice*. New York, New York: Oxford University Press, 2000.
- Nussbaum, Martha C. *Women and Human Development: The Capabilities Approach*. Cambridge, United Kingdom: Cambridge University Press, 2000.
- Pascal, Blaise. *Pensées*. Edited and translated by A.J. Krailsheimer. London, United Kingdom: Penguin Books Ltd, 1995.
- Pettit, Philip. *A Theory of Freedom: From the Psychology to the Politics of Agency*. New York, New York: Oxford University Press, 2001.

- Plato. *The Dialogues of Plato: Translated into English with Analyses and Introductions* vol. 3. Edited and translated by Benjamin Jowett. London, United Kingdom: MacMillan and Company, 1892.
- Pogge, Thomas. "Can the Capability Approach be Justified?" *Philosophical Topics* 30, no. 2 (Fall 2002): 167-228.
- Quayson, Ato. *Aesthetic Nervousness: Disability and the Crisis of Representation*. New York, New York: Columbia University Press, 2007.
- Rawls, John. *Political Liberalism: With a New Introduction and The "Reply to Habermas"*. New York, New York: Columbia University Press, 1993.
- Rawls, John. *A Theory of Justice: Revised Edition*. Cambridge, Massachusetts: The Belknap Press of the Harvard University Press, 1999.
- Richards, Christopher T., LaVera M. Crawley, and David Magnus. "Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: Inconsistencies in standards across major pediatric transplant centers." *Pediatric Transplantation* 13 (2009): 843-850.
- Richardson, Henry. "Rawlsian Social-Contract Theory and the Severely Disabled." *The Journal of Ethics* 10 (2006): 419-462.
- Rivas, Lynn May. "Invisible Labors: Caring for the Independent Person." In *Global Women: Nannies, Maids, and Sex Workers in the New Economy*. Edited by Nancy Ehrenreich and Arlie Russell Hochschild. New York, New York: Henry Holt and Company, 2002.
- Rivera, Chrissy. *The Real Story About Wolf-Hirschhorn Syndrome* (blog). [http://www.wolfhirschhorn.org/2012/01/amelia/brick walls/](http://www.wolfhirschhorn.org/2012/01/amelia/brick%20walls/)
- Robeyns, Ingrid. "The Capability Approach in Practice." *The Journal of Political Philosophy* 14, no. 3 (2006): 351-376.
- Rousseau, Jean-Jacques. *The Social Contract and the First and Second Discourses*. Edited by Susan Dunn and translated by Lester Crocker and Susan Dunn. New Haven, Connecticut: Yale University Press, 2002.
- Russell, Bertrand. *Principles of Social Reconstruction*. London, United Kingdom: Routledge Publishers, 1997.
- Russell, Marta. *Beyond Ramps: Disability at the End of the Social Contract*. Monroe, Maine: Common Courage Press, 2002.

- Santayana, George. *The Life of Reason; Or, The Phases of Human Progress: Reason in Society*. New York, New York: Scribner and Sons, 1906.
- Schalock, Robert A. *Quality of Life: Perspectives and Issues*. Edited by Robert A. Schalock. Washington, D.C.: American Association on Mental Retardation, 1990.
- Schweik, Susan M. *The Ugly Laws: Disability in Public*. New York, New York: New York University Press, 2009.
- Secretary General of the United Nations. *Right of everyone to the enjoyment of the highest attainable standard of physical and mental health*. Aug 10 2009. (A/64/272). Available online through <http://documents.un.org/>.
- Sen, Amartya. *Development as Freedom*. New York, New York: Anchor Books, a division of Random House, 1999.
- Sen, Amartya. *Equality of What?: The Tanner Lectures on Human Values*. Found at , <http://www.tannerlectures.utah.edu/lectures/documents/sen80.pdf>.
- Sen, Amartya. *The Idea of Justice*. Cambridge, Massachusetts: The Belknap Press of Harvard University Press, 2009.
- Sen, Amartya. *Inequality Reexamined*. Cambridge, Massachusetts: Harvard University Press, 1992.
- Siebers, Tobin. "What Can Disability Studies Learn from the Culture Wars?" *Cultural Critique* 55 (2003): 182-216.
- Silvers, Anita and Leslie Pickering Francis. "Justice through Trust: Disability and the 'Outlier Problem' in Social Contract Theory." *Ethics* 116 (Oct. 2005): 40-76.
- Singer, Peter. *Practical Ethics*. New York, New York: Cambridge University Press, 1993.
- Singer, Peter. *Rethinking Life and Death: The Collapse of our Traditional Ethics*. New York, New York: St. Martin's Griffin, 1994.
- Singer, Peter. *Writings on an Ethical Life*. New York, New York: Harper Collins Publishers, 2000.
- Singer, Peter. "Why We Must Ration Health Care." *New York Times Magazine*, July 15, 2009.
- Slavishak, Edward. "Artificial Limbs and Industrial Workers' Bodies in Turn-of-the-Century Pittsburgh." *Journal of Social History* 37, no. 2 (Winter 2003): 365-388.

- Sophocles. "Antigone." In *World Drama: An Anthology, Vol.1: Ancient Greece, Rome, India, China, Japan, Medieval Europe, and England*. Edited by Barrett Clark and translated by Sir George Young. New York, New York: Dover Publications, 1960.
- Stein, Mark S. "Utilitarianism and the Disabled: Distribution of Life." *Social Theory and Practice* 27, no. 4 (October, 2001): 561-578.
- Stone, Christopher D. *Should Trees Have Standing?: and other essays on law, morals, and the environment*. Dobbs Ferry, New York: Oceana Publications, 1996.
- Universal Declaration of Human Rights, available at <http://www.un.org/en/documents/udhr/index.shtml>
- UN Convention on the Rights of Persons with Disabilities. *Committee on the Rights of Persons with Disabilities, Second Session, Summary record of the 6th meeting*. Held at the Palais des Nations, Geneva, on Wednesday, 21 October 2009. . (CRPD/C/2/SR.6). Available online through <http://documents.un.org/>
- Verhagen, Eduard, J.J. Sol, O.F. Brower, and Pieter Sauer. "Deliberate Termination in Life of Newborns in the Netherlands; Review of All 22 Reported Cases between 1997 and 2004." *Ned Tijdschr Geneeskde*. 149, no. 4 (January 22, 2005): 183-188.
- Verhagen, Eduard and Pieter Sauer. "The Groningen Protocol—Euthanasia in Severely Ill Newborns." *The New England Journal of Medicine* 352, no. 10 (March 10, 2005): 959-962.
- Walbert, Renee. Parent to Parent of Colorado. [p2p-co@yahoo.com], posted 10 May 2012 [cited 27 May 2012].
- Ward, Nancy. "Reflections on My Quality of Life: Then and Now." In *Quality of Life: Perspectives and Issues*. Edited by Robert A. Schalock. Washington, D.C.: American Association on Mental Retardation, 2009.
- Ward, Nancy. "Self-Advocates." In *What We Have Done: An Oral History of the Disability Rights Movement*. Edited by Fred Pelka. Amherst, Massachusetts: University of Massachusetts, 2012.
- Wehmeyer, Michael L. "Employment Status and Perceptions of Control of Adults with Cognitive and Developmental Disabilities." *Research in Developmental Disabilities* 15, no. 2 (1994): 119-131.
- Wehmeyer, Michael L. and Michelle Schwartz. "The Relationship Between Self-Determination and Quality of Life for Adults with Mental Retardation." *Education*

and Training in Mental Retardation and Developmental Disabilities 33, no. 1 (1998): 3-12

Williams, Bernard. "The Human Prejudice." In *Peter Singer Under Fire: The Moral Iconoclast Faces His Critics*. Edited by Jeffrey A. Schaler. Peru, Illinois: Carus Publishing Company, 2009.

Wixon, Colleen. "Autistic Student, Mom Receive Worldwide Support." *TCPalm*, 29 May 2008. <http://www.tcpalm.com/news/2008/may/29/30gt-autistic-student-mom-receive-worldwide-hed/>

Wollstonecraft, Mary. *A Vindication of the Rights of Woman*. Edited by Miriam Brody. London, United Kingdom: Penguin Books Ltd., 2004.